Menstrual Support for Females with Developmental Disabilities:

Survey and Interview of Parents or Caretakers

By

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Submitted to the graduate degree program in Special Education and the Graduate Faculty of the University of Kansas in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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ABSTRACT

Menstruation is a difficult topic to address with as females with or without disabilities. It is a more significant challenge for females with developmental disabilities (DD) because it stimulates a variety of physical and psychological changes. Thus, some females with DD might have a qualitatively different experience compared to the general population. In this study, an online survey and follow up telephone interviews of parents/caretakers of females with DD were conducted in order to investigate how they manage menstruation, the kind of support or help needed or currently given to females to manage menstruation. The results of the study generated quantitative data for the survey study and qualitative data for the interview study. In order to examine the hypotheses of the survey study, bivariate tests (Wilcoxon-Mann-Whitney test, correlation) were conducted. A total of 61 participates (parents or primary caretakers of females with DD) completed the survey via SurveyMonkey™. The results showed that the mild and moderate group (M/M group) tended to be more independent on menstrual management, sought more educational support, and training and recourses related to menstrual management than the severe and profound group (S/P group). The interview study used semi-structured interviews to examine the research questions. Total five participants were interviewed. Overall, the results indicated that parents or caretakers of females with DD had negative experiences of menstrual management and they need more support and resources not only for themselves but also for females with DD.

ACKNOWLEDGEMENTS

First, I would like to thank my advisor, Dr. Deborah Griswold, who was my big supporter during the long journey of the doctoral program and gave me the encouragement to accomplish the dissertation. You know that I would not have made it through without you. You provided me with a lot of rich experiences to build up my professional career as a doctoral student in special education. To Dr. Richard Simpson, Earl Knowlton, Vicki Peyton, Don Deshler, and Arlene Barry, I want to acknowledge and thank your support and help as my committee members. To Dr. Gary Clark, you always popped up in front of me whenever I needed a hug. Thank you so much for your help!

To my husband Jason, I finally finished my dissertation. I know you have waited for a long time to see my accomplishment. I truly thank you for your care and love as a husband and friend. I am very lucky to have you. I appreciated your good advice for the quantitative study part. I would not have finished it without your help. To Louie and Lena, both of you spent time with me while I was working on my dissertation. God sent you to me in order to make my life and my degree more worthy.

To my parents, thank you for giving me such a grateful opportunity to study here at the University of Kansas. I know it was not an easy decision to let me go to the U.S. I am sorry that it took so long to get my degree. I promised I would not give up and get my doctoral degree, and finally I did it!

To my brother Joon Woo Park, you inspired me to begin with my interest in special education. Although you could not do your role as the first son and elder brother due to your disability, you raised me as a person who cares about people with disabilities with a warm heart. I am so sorry that I have been away from you for a long time to study here in the U.S. I am not going to feel sad while thinking about you. Instead I will be smiling. I love you so much!

Finally, special thank for Angel, Youjin, Sukjung, and Hyojung! Because of your help and support, I was able to finish my dissertation defense without worries of Louie and Lena. Thank you so much for being such good friends. I will never forget your help and your love.

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CHAPTER 1

Introduction

According to the American Academy of Family Physicians, puberty in US females typically has an onset between 8 and 13 years of age. Among children with cerebral palsy, puberty tends to begin earlier and end later than in typically developing children (`Worley, Houlihan, & Herman-Giddens, 2002). In general, children with developmental disabilities (DD) are 20 times more likely to experience early pubertal changes (Siddiqi, Van Dyke, Donohoue, & McBrien, 1999). Although idiopathic precocious puberty, which is defined as the development of sexual characteristics before the age of eight years (Prété1, Couto-Silva, Trivin, & Brauner, 2008) occurs in approximately 1 in 1000 girls, 20% of the incidence is among females with spina bifida (Elias & Sadeghi-Nejad, 1994). Precocious puberty can further challenge females with DD, who may be socially immature by affecting an already altered body image and self-esteem, increasing the complexity of self-care and hygiene activities, and heightening the risk of sexual victimization (Heger, Sippell, & Partsch, 2005).

Menarche (first menstruation) is one of the puberty symptoms for all females. Menarche has a significant impact on every female's development because it stimulates a variety of physical and psychological changes (Beausang & Razor, 2000; Havens & Swenson, 1986; Sulpizi, 1996). It might be expected that some females with DD will have a qualitatively different experience compared to the general population (Mason & Cunningham, 2008).

Developmental disabilities (DD) are severe chronic conditions that are due to mental or physical impairment or a combination of both. DD are manifested before the person attains age twenty-two and usually last throughout a person's lifetime. People with developmental disabilities may have problems with major life activities such as language, mobility, learning, self-help, and independent living. Examples of conditions in the developmental disabilities

population include intellectual disability, deafness, blindness, cerebral palsy, Down syndrome, and autism (Yeargin-Allsopp, Murphy, Oakley, & Sikes, 1992).

Females with DD tend to have difficulty following and implementing standard menstrual hygiene routines because of their lack of self-help skills, but do vary with cognitive, sensory, and/or motor abilities. This fact may challenge not only the individuals with DD but also their families or caretakers. Furthermore, several studies have shown an increase in problem behaviors, emotional problems, and seizure frequency at certain stages of the menstrual cycle due to cyclical hormonal changes and menstrual cramping. This is especially true when behavioral changes can be related to menstrual cramping and pain. The behavior seen in females with DD may include aggression, restlessness, hyperactivity, increased agitation, and self-mutilation (Backeljauw, Rose, & Lawson, 2004; Backstrom, 1976).

Although menstrual issues (e.g., menstrual-care skills, menstrual problems) have been problematic for females with DD for decades, not much research has been conducted. The existing research in the area of teaching functional skills of any type to individuals with intellectual disabilities was conducted, for the most part, since the early 1960s. This research resulted in numerous programs based on behavioral instructional methods that address how to teach a variety of self-help repertories such as toileting (Azrin & Foxx, 1971), dressing (Minge & Ball, 1967), tooth brushing (Horner & Keilitz, 1975), and feeding (Barton, Guess, Garcia, & Bear, 1970). Despite the development of various self-help instructional methods, the problem of menstrual care for females with intellectual or other developmental disabilities remains an area in which no widely accepted programs are available. Only a few studies have addressed the problem, and none have provided a documented, replicable study or solutions.

Purpose of the Study

There is a paucity of research on menstrual care for females with developmental disabilities (DD). In order to determine and provide appropriate and effective menstrual-care

skills or support for females with DD, it is necessary to investigate the needs of parents/caretakers of females with DD. The purpose of this study was to survey and interview parents/caretakers of females with DD about how to manage menstruation and what kind of support (education or training) or help was needed or is currently given to females to manage menstruation. The results of the study were intended to generate data that shows what the parents/caretakers need for the females with DD related to menstrual management issues and identify what kinds of future actions will be needed for them. The interview data were intended to provide additional information for the purpose of discussion.

In this study, developmental disabilities included moderate to profound disabiltiies, intellectual disability, deafness, blindness, Down syndrome, cerebral palsy, and autism spectrum disorders. The following research questions and hypotheses were investigated in this study.

Research Questions Related to the Survey Study

Research Question 1: What are the levels and traits among females with DD in terms of degree of independence, educational needs, and information accessibility related to menstrual care?

Hypothesis 1: Females with mild or moderate DD are more independent in menstrual care than females with severe or profound DD.

Hypothesis 2: Parents or caretakers of females with mild or moderate DD seek more educational training or teaching for menstrual management compared to parents or caretakers of females with severe or profound DD.

Hypothesis 3: Parents or caretakers of females with mild or moderate DD seek more resources for menstrual management compared to parents or caretakers of females with severe or profound DD.

Research Question 2: Are there any associations between degree of independence,

educational needs, and information accessibility and disability-related characteristics (type and severity), after controlling for parents' or caretakers' socio-demographic characteristics (e.g., age, ethnicity, marital status, education level, employment)?

Research Questions Related to the Interview Study

Research Question 1: How do levels of disability affect parents' or caretakers' expectations of menstruation management?

Research Question 2: What kinds of problems do the parents/caretakers and girls with DD experience with menstruation?

Research Question 3: What kinds of support do parents/caretakers want to receive for girls with DD?

Research Question 4: How did parents/caretakers communicate with girls with DD to manage menarche or menstruation?

Research Question 5: What systems of support did the mothers have access to during the transition to menarche? Were those supports helpful?

Definition of Degrees of Severity of Disability

The present study included females with mild, moderate, severe, and profound disabilities in order to examine the research questions related to the survey study. For the classification of the four different levels (mild, moderated, severe, and profound) of intellectual disabilities, the Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision (DSM-IV-TR; APA, 2000) was used in this study. After completion of the study, the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-V; APA, 2013) was published. While DSM-VI used IQ scores and adaptive functioning to define the various levels of serenity, the DSM-V used only adaptive functioning because IQ measures are less valid in the lower end of IQ range (APA, 2013).

Mild mental retardation. According to DSM-IV-TR (APA, 2000), Intellectual quotient (IQ) scores for individuals with a mild intellectual disability range from 50 to approximately 70. Most people in this range have minimal impairment in the sensory-motor area, so they are not often distinguished from individuals without a disability. Academic skills that they might be expected to acquire is up to approximately the sixth-grade level by late teens. With appropriate support, people with mild intellectual disabilities achieve social and vocational skills. Most are expected to have a successful life in the community (APA, 2000).

Moderate mental retardation. IQ scores for individuals with moderate intellectual disabilities are from 35 to 55. In most cases, communication skills are acquired during the early childhood years. Vocational, social, and occupational training may be acquired with moderate supervision, but academic attainment beyond the second grade level is not generally expected. Social relationships and traveling to unfamiliar places are challenging. They typically are able to adapt well in a community setting to live and work with supervision (APA, 2000).

Severe mental retardation. IQ scores for individuals with severe intellectual disabilities are from 20 to 40. They may master very limited and basic self-care and some communication skills. Their academic skills are limited to the pre-academic skills such as learning some "survival" words. They can perform simple tasks under close supervision. Many individuals with severe intellectual disabilities are able to adapt well in community, group homes, or with their families **(**APA**,** 2000**)**.

Profound mental retardation. IQ scores for individuals with profound intellectual disabilities are below 20 or 25. They display considerable sensorimotor functioning impairments during their early childhood years. They may be able to develop basic self-care, motor development, and communication skills with appropriate and private support and

training in a highly structured environment. Their retardation is often caused by an accompanying neurological condition (APA, 2000).

CHAPTER 2

Review of Literature

This chapter contains a review of existing literature on the following topics: (1) menarche and menstruation for females in general, (2) history of females' health for developmental disabilities (DD), (3) menarche and menstruation for females with DD, (4) menstrual management approaches for females with DD, (5) mothers' or caretakers' of females with DD reactions to menarche, (6) menstrual problems, (7) communication between females with DD and mothers or caretakers to manage menarche and menstruation, (8) systems of support during the transition to menarche, (9) effectiveness of the supports, (10) preferred types of supports or needs, and (11) current available supports or resources.

Menarche and Menstruation for Females in General

Even though menstruation is a universal female experience, menarche, or first menstruation, can elicit a wide range of responses from young females and their caretakers. In mainstream Western society, menstruation is often a taboo subject, hidden from others and discussed only with close friends or female relatives (Abraham et al., 1985; Beausang & Razor, 2000; Costos, Ackerma, & Paradis, 2002; Gray & Jilich, 1990). In contrast, in the other half of the world's cultures, menarche is celebrated with rituals and ceremonies as a religious, community, or economic event (Brooks-Gunn & Ruble, 1982; Paige, Paige, & Fuller, 1981). In other words, the developmental transitions to puberty and menarche are viewed and valued differently across cultures and family systems (Beausang & Razor, 2000). Therefore, cultural context should be considered in examining transition events, family resilience, and socially private topics (Carlson & Wilson, 1994; Costos, Ackerman, & Paradis, 2002; Hawley & DeHaan, 1996).

Typically, most of the information about menarche and menstruation comes from mothers, school teachers, media, and peers, often in the context of discussions on hygiene and

menstrual symptomatology (Morse & Doan, 1987; Whisnant & Zegans, 1975). For most young females, cultural beliefs that menstruation is associated with physical discomfort, increased emotionality, and disruption of activities and social interactions are well entrenched even before menarche (Brooks-Gunn & Ruble, 1982; Clarke & Ruble, 1978; Koff & Rierdan, 1995; Whisnant & Zegans, 1975).

Beausang and Razor (2000) examined young females' experiences of menarche and menstruation. Most of the participants described their experiences as negative.

Several respondents desired more information from educators. This study suggested that mothers need information and support to teach their daughters more effectively. In school settings, curriculums need to be strengthened to include the biological processes of menstruation. Lastly, embarrassment must be minimized by strategies such as working with small groups or individuals.

Symptoms or experiences of menstruation for females with DD may be different or identical to those of typical females without disabilities. In order to observe the differences and similarities, the following section will address the historical aspect of females' health and menstrual experiences and menstrual management approaches for females with DD.

History of Females' Health for DD

Historically, individuals with DD were under recognized, separated, and systemically dehumanized in society (Saltonstall, 2009). Indeed, individuals with DD are fundamentally different from the rest of society so that they cannot exist in the community without assistance (Ellis, 1975). Therefore, individuals with DD took on others' fears and prejudices and have been singled out for special treatment and forced sterilizations (Werner, 1988; O'Hara & Sanks, 1956). Especially, sterilization as a treatment was performed without appropriate regard to the individuals' decision-making capacities, abilities to care for children, feelings, and interests of females with DD. Such decisions should be made only in the context

of the individuals' capacity to make a decision, the consequence of reproduction for the person and any children that might be born, and applicable local, state, and federal laws (American Academy of Pediatrics, 1999; Silber & Batshaw, 2004).

The presumptions about individuals with DD combined with imperfectly understood principles of genetics and advances in medical sterilization procedures led to a brief period of popularity for eugenic sterilizations in the early decades of the 20th century (Cynkar, 1981). Specifically in 1927 the United States Supreme Court declared constitutional a Virginia statute authorizing the involuntary sterilization of institutionalized "mental defectives" (Buck v. Bell). The justifications under the state's exercise were: (1) "the prevention of the inheritance of the condition, therefore reducing the number of mental defectives," (2) "the fear that too many mental defectives would become a *social menace*," and (3) "the interest in reducing the costs of institutionalization."

Nevertheless, realistically the study of eugenics on DD was not able to advance due to the wide gaps in knowledge about how genetics actually work (Cynkar, 1981). The legal ramifications of the eugenics movement, however, have proved much more durable. Simultaneously, the state's interests in requiring sterilization started outweighing the rights of a person with retardation (Vitello, 1978). In addition, the various movements (de-instutionalization and disability rights movements) in the US, in the 1970s affected the rights of females with disabilities (Kempton & Kahn, 1991) although cultural taboos and limited knowledge of females with disabilities still existed in society during those years.

Menarche and Menstruation for Females with DD

In general menstrual management for females with DD has been viewed as problematic. Much less is known about the perspectives and experiences of primary caregivers during a girl's development through early menstruation in the context of disability (Carlson & Wilson, 1994). Despite the importance of issues related to puberty and

menstruation, individuals with disabilities and their families are often given limited information and deprived of appropriate services (Gill, Kirschner, & Reis, 1994; Oshima, Kirschner, Heinemann, & Semik, 1998). Many parents of girls with DD often felt very anxious about the visible markers of her sexuality because they think they are unable to manage their daughter's disability (Demetral, Driessesn, & Goff, 1983). Furthermore, only in the past two decades has sex education and support for sexual expression become important to researchers and professionals (Ames, 1991; Cambridge & Mellan, 2000; Kempton & Kahn, 1991; Williams & Nind, 1999); and for many years little research investigated the perspectives of females with developmental disabilities (Rodgers, Lipscombe, & Santer, 2006). Although several publications have addressed contraceptive management in females with intellectual disabilities, Down syndrome, or learning disabilities (Quint, Breech, Bacon, & Schwandt, 2006) review of the available literature revealed a lack of specific guidelines addressing the unique problems related to menstruation in this particular group of adolescents and even more, most of the studies revealed no data to support their statements (Backeljauw, et al., 2004). Historically, there has been a greater focus on menstrual suppression or elimination than on help and training to manage menstrual care successfully (Carlson, 2002; Carlson & Wilson, 1994).

Menstruation management approaches have been viewed as two parts, medical and educational responses. It is necessary to review how those two different approaches have affected females with DD both in negative and positive ways.

Menstrual Management Approaches for Females with DD

Medical approaches for menstrual care. A variety of medical options are available to address the various concerns that caregivers have regarding adolescent girls with developmental disabilities. These options must meet the needs of females affected by a wide spectrum of developmental disabilities: a group ranging from high functioning adolescents

with mild cognitive impairments who are actively involved in school and extracurricular activities, to severely handicapped adolescents who require complete care for all activities of daily living. A recent retrospective review of clinical characteristics and management of young females with developmental delay referred to a pediatric gynecology clinic revealed that while the primary purpose for consultation was menstrual related in 90% of the cases, nearly half of the patients seen were still premenarchal. These early consultations highlight caregiver anxiety about coping with menstruation and the need for counseling and education about what to expect and about available options (Savasi, Spitzer, Allen, & Ornstein, 2009). To address the problems associated with the menstrual-care needs of individuals with intellectual disabilities, medical procedures rather than educational approaches have often been the recommended treatment (Richman, Ponticas, Page, & Epps, 1986). Several studies have reported parental approval of surgical hysterectomy for their daughters with intellectual disabilities as a means of eliminating menstrual care problems (Turchin, 1974). Others have cited specific cases in which hysterectomies were performed at least in part due to menstrual hygiene concerns (Alcorn, 1974; Bass, 1978; Crain, 1980; McNamara, Scoggin, & Raskin, 1974; Perrin, Stands, Tinker, Dominquez, Dingle, & Thomas, 1976). However, the use of nontherapeutic hysterectomies has raised numerous ethical and legal concerns (Crain, 1980; West, 1977). Since 1974, there has been a moratorium on the use of federal funds for involuntary sterilization or for sterilization of persons under the age of 21 (Dowben & Heartwell, 1979). The central issue related to sterilization of mentally retarded persons concerns consent (“DHEW Proposes,” 1978), and the question of the individual’s capacity to give informed consent. Another medical intervention sometimes recommended is the use of drugs to control menstruation (Roxburgh & West, 1973; Shropshire, Morris, & Foote, 1967). Although the prescription of such medication circumvents legal problems associated with surgical procedures, their use is not without side effects, and long-term studies have yet to be

done. Moreover, drug therapy should not be considered the treatment of choice if less intrusive interventions are available.

Educational approaches for menstrual care skills. Research in the area of training functional skills to the population with developmental disabilities has focused on the numerous programs for teaching a variety of self-help repertories. A technology based on behavioral instructional methods for self-help skills emerged in the late 1960s and 1970s and has been shown to be successful in teaching skills (Azrin & Foxx, 1971; Minge & Ball, 1967; Horner & Keilitz, 1975; Barton, Guess, Garcia, & Bear, 1970). Despite the development of this well-defined technology, the problem of menstrual care in individuals with mental retardation remains an area in which no widely accepted programs are available. Among the limited research publications, only a few studies have addressed the problem, and none have provided a documented, replicable problem as evidence. The earliest studies on menstrual management skills for disabilities were the empirical study conducted by Girardeau and Spradlin (1964) and, that of Hamilton, Allen, Stephens, and Davall (1969). The study by Girardeau and Spradlin (1964) was conducted with girls with moderate and severe/profound disabilities in a residential center. This study reported that the initial stages of using sanitary napkins with positive reinforcement was included as one of several self-care training goals, but specific procedures were not described and results were not discussed. The study by Hamilton et al. (1969) also was conducted for females with disabilities in an institution. This study described a 5-step procedure for teaching females with intellectual disabilities to change sanitary napkins as a general self-help skill. It was difficult to conclude, however, that the training procedure per se was the functional variable because no experimental design was used. In the 1970s publications by several researchers (Bender & Valletutti, 1976; Bender, Valletutti, & Bender, 1976; Zelman & Tyser, 1979), the materials were commercially available. These publications were designed specifically to teach menstrual care skills to

females with intellectual disabilities. Like other earlier reports or publications, none of these were empirically evaluated. Another training guide by Hamre-Nietupski and Williams (1977) developed a simulated premenstrual training program to teach two students as a part of a sex education program, prior to the beginning of menstruation, to identify their menstrual period and then follow a hygienic routine. Although the authors reported that this program was effective, no data were presented to show the continued effectiveness of the program once menses occurred.

While socio-cultural and legal attitudes towards sterilization and fertility management were shifting, the new concept of management skills using educational method was emerging and more preferred than medical interventions (Saltonstall, 2009) in the 1980s. Therefore, several publications introduced more naturalistic treatment, use of simulated teaching, and involvement of non-specialized staff to implement treatment (Demetral, Driessen, & Goff, 1983; Richman, Ponticas, Page, & Epps, 1986; Richmans, Reiss, Bauman, & Bailey, 1984).

The study by Demetral et al. (1983) investigated the preparatory education for the first menstruation, which is the only empirical research on the preparation for menarche to date. The educational program was to teach 12 females with DD the menstrual process in the necessary feminine hygiene skills, discriminations and behavioral repertories. The discriminations and behavioral repertories included (a) the visual and cognitive recognition of the menarche, “red” fluid, (b) recognition of the need for the certain types of hygiene materials, and (c) behavioral requirements of how to appropriately dispose of the pads. Each of three phases for the discriminations and behavior repertories was specifically described. This single-subject design study indicated that the researcher measured generalization and social validation, but did not report the result. Study results were provided as an anecdote without providing any data.

The research by Richman et al. in 1984 and 1986 conducted the menstrual care studies using a single subject design using applied behavior analysis. These studies reported several problems encountered when females with intellectual disabilities did not possess the skills essential for menstrual care. Richman et al. (1986) used a simulation training procedure whereby adolescents with intellectual disabilities acquired independent menstrual care skills. These skills were taught by modeling with an anatomically correct doll, and skill generalization to the adolescent was measured. The results showed that the skill did generalize. Follow-up measures taken during actual menses showed that the girls retained the skills and used them appropriately during menses up to several months post treatment.

Epps, Stern, and Horner (1990) used a multiple-baseline design across subjects to examine the effects of two simulation methods of general case instruction in teaching generalized menstrual care for three young females with severe intellectual disabilities and one adult woman with profound intellectual disabilities. This research was a long-term maintenance study up to 18 months. The two participants received both doll training and instruction on self. The target behavior consisted of four components by demonstrating on them or by manipulating the doll: (a) changing stained underwear, (b) changing stained pads, (c) changing stained underwear and pads, and (d) not changing underwear or obtaining a pad in the absence of a stain. This study extended earlier studies (Richman et al., 1984; Richmam et al., 1986). Although further replicated studies are needed to prove the effectiveness of the training strategy, this study showed that all of the participants demonstrated high levels of generalized responding following on-self instruction.

Griffin, Carlson, Taylor, and Wilson (1994) conducted a case study for each of six females who had an intellectual disability. This study developed a model of intervention to assist with menstrual management for females with high support needs. The key areas of intervention are the following: (a) assessment of the females' actual or potential menstrual

management skills; (b) increasing awareness of attitudes towards menstruation for females who have intellectual disability, among people assisting them; and (c) provision of a range of information, processes and resources to assist educators, families, and others providing personal assistance, with informed menstrual management for these females. The results of this study indicated positive gains made by four of six participants.

The recent study by Klett and Turan (2012) conducted a multiple baseline design study in order to examine the effectiveness of Social Story intervention with an embedded visual task analysis to teach menstrual management skills and knowledge to three young females with autism spectrum disorders (ASD). The Social Story was developed by researchers and it contained three different parts, (1) Growing up, (2) My period, and (3) How to take care of my period. Parents of the young females with ASD were trained to implement the Social Story intervention with an embedded visual task analysis. The implementation sessions took place in a home setting and social validity of target behaviors, intervention procedures and intervention effects were evaluated by researchers. The results of the study clearly indicated that all of the participants increased their skills in changing a sanitary pad. The parents were satisfied with the intervention and they reported intervention was helpful for teaching menstrual care skills and knowledge to females with ASD.

Mothers' or Caretakers' of Females with DD Reactions to Menarche

The experiences of mothers (caretakers) or females with DD are vast and varied (Saltonstall, 2007); therefore, their reaction or actions about menarche are diverse as well. As Table 1 shows below, only one study (Carlson & Wilson, 1994) found that 46.7% of participants had their menstruation permanently eliminated through surgery between 10 and 17 years of age (average 14.3 years) as an action. Additional mothers of the participants were considering surgery resulting in menstrual elimination. Concerning her daughter's menarche, one mother stated she was expecting the worst, was dreading it, and was afraid of it (Carlson

& Wilson, 1994). Mason and Cunningham (2008) reported that females with Down syndrome, who felt they had not been provided any preparation, described their menarche as a ‘shock’ or ‘surprise’ while others who had been prepared for menarche seemed to find the process far less difficult. One participant in the Ditchfield and Burns’ study (2004) stated that the menarche was traumatic and scary. In some cases reported in the studies (Mason & Cunningham, 2008; Saltonstall, 2007), there were very different types of reactions to menarche. The participants were looking forward to starting their periods and “becoming a woman.” One participant stated she was thrilled when she started it. Another mother was unique in her direct expression of additional excitement that her daughter had reached “womanhood,” “proud,” and “excitement” (Saltonstall, 2007).

Table 1

Summary of Mothers' or Caretakers’ Reactions

Study	Carlson & Wilson (1994)	Ditchfield & Burns (2004)	Mason & Cunningham (2008)	Saltonstall (2007)
N	30 (mothers)	11 (mothers)	59 (mothers)	4 (mothers)
Positive reaction	Not answered	Not answered	Feeling thrilled Looking forward to starting their periods and ‘becoming a woman’ positive comments (some mothers)	Additional excitement of reaching “womanhood” And feeling proud (25%; *n* = 1)
Negative reaction	Menstruation elimination (46.7%; *n* = 14) Considering menstrual elimination (26.7%; *n* = 8) Feeling dreaded and afraid (3.3%; *n* = 1)	Traumatic and scary (9.1%; *n* = 1)	Shocked and surprised (8.5%; *n* = 5)	Surprised due to a perception that their daughter was young for menarche (50%; *n* = 2) Worried (25%; *n* = 1)

Menstrual Problems for Females with DD

Participants in 10 studies (Carlson & Wilson, 1994, 1996; Chou et al., 2008, Ditchfield & Burns, 2004; Epps, Stern, & Horner, 1990; Griffin, Carlson, Taylor, & Wilson, 1994; Mason & Cunningham, 2008; Rodgers & Lipscombe, 2005; Rodgers et al., 2006; Saltonstall, 2007) reported a range of emotional, physiological, and management problems relating to menstruation. These problems include pain, menorrhagia (heavy periods), lengthy or irregular periods, inappropriate behavior and mood changes, negative reactions, hygiene problems, self-care, and other problems. Due to the various numbers of participants across the studies, Table 2 presents the percentages and numbers of participants in order to enhance the understanding of the results.

Table 2

Percentages of Menstruation Problems (Number of Participants in Parentheses)

	Carlson & Wilson (1994)	Carlson & Wilson (1996)	Chou et al. (2008)	Chou & Lu (2012)	Ditchfield & Burns (2004)	Rodgers et al. (2006)	Mason & Cunningham (2008)	Rodgers & Lipscombe (2005)	Saltonstall (2007)
N	24 [a]	63	55	12	11	408 [b]	59	367 [c]	4
Pain	33.3 (8)	22.2 (14)	71.4 (30) [d]	Not Sure	90.9 (10)	53.7 (219)	11.9 (7)	N/A	N/A
H,L,I period	N/A	12.7 (8)	N/A			N/A		N/A	N/A
Heavy		N/A		N/A	81.8 (9)	30 (123)	18.6 (11)		
Lengthy		N/A		N/A	N/A	8 (32)	0 (0)		
Irregular		N/A		25 (3)	N/A	27 (109)	13.6 (8)		
Behavior change	N/A	N/A	N/A	50 (6)	N/A	15 (59)	N/A	N/A	N/A
Mood change	N/A	N/A	16.7 (7) [b]	83.3 (1)	72.7 (8)	51 (208)	N/A	N/A	N/A
Negative reactions	41.7 (10)	14.3 (9)	A few	N/A	90.9 (10)	N/A	N/A	N/A	N/A
Hygiene problem	0 (0)	22.2 (14)	N/A	N/A	N/A	50 (202)	N/A	N/A	N/A
Self-care		N/A			N/A	N/A			N/A
High (Independent)	8.3 (2)		47.3 (26)	100 (12)				49.6 (183) [e] 35.9 (132) [f] 24.7 (89) [g] 48.2 (177) [h] 43.6 (159) [i]	N/A

Table 2

Percentages of Menstruation Problems (Number of Participants in Parentheses) (Continued)

Variable	Carlson & Wilson (1994)	Carlson & Wilson (1996)	Chou et al. (2008)	Chou & Lu (2012)	Ditchfield & Burns (2004)	Rodgers et al. (2006)	Mason & Cunningham (2008)	Rodgers & Lipscombe (2005)	Saltonstall (2007)
Medium (With help)	37.5 (9)		16.4 (9)					14.4 (53) [e] 26.1 (9) [f] 16.7 (60) [g] 20.4 (75) [h] 19.5 (71) [i]	N/A
Low (Dependent)	54.2 (13)		18.2 (10)					36 (133) [e] 38 (140) [f] 58.6 (211) [g] 31.3 (115) [h] 37 (135) [i]	N/A
Preparation	37.5 (9)	20.4 (10)	N/A	N/A	0 (0)	N/A	91.5 (54)	N/A	50 (2)
Teaching menstrual care	50 (12)	N/A	N/A	N/A	N/A	N/A	N/A	71(261)	75 (3)

Note. In the study by Rodgers and Lipscombe (2005), the independent levels were reported in the five different tasks of menstrual self-care. Due to rounding, the percentages may not always equal 100%. Ninety seven (22%) of the females had not menstruated within the past 6 months.

[a]24 of 30 participants responded to the questions related to the menstruation problems.

[b]408 of 452 participants responded to the questions related to the menstruation problems.

[c]367 of 542 participants responded to the questions related to the independent level of changing pads/tampons.

[d]42 of 55 participants responded to the questions related to pain, and 30 of 42 participants reported pain was a problem during menstruation.

[e]This number is for whom identified when period started.

[f]This number is for whom managed keeping clean during period.

[g]This number is for whom obtained pads/tampons.

[h]This number is for whom changed pads/tampons.

[i]This number is for whom disposed of pads/tampons.

Pain. Pain was one of the menstrual symptoms most often reported in the target studies. Across six studies (Carlson & Wilson, 1994; Cho et al, 2008; Ditchifield & Burns, 2004; Mason & Cunningham, 2008; Rodgers et al, 2006), participants who reported abnormal pain during the menstrual period ranged from 22.2% to 90.9% (*M* = 54.3%). In particular, Carlson and Wilson (1994) reported 33.3% of the participants experienced pain associated with menstruation and another study by Carlson and Wilson (1996) reported that 22% of the participants had experience with abdominal pain or distension.

Chou et al. (2008) indicated 37.5% of the participants felt abnormal pain. Rodgers et al. (2006) reported that 54% of the participants had experienced abnormal period pain, which was the most frequent problem experienced in the last 6 months. Ditchfield and Burns (2004, p. 28) reported that 91% of the participants described pain as a significant negative impact on their lives, for example, ” “agony,” “like the bones in me are pulling out,” and “I can’t move because of the pain.”

Some of the studies presented different kinds of approaches that participants reported they used: massage, herbal medications, and pain relieving medication (Carlson & Wilson, 1994) and warm water or sweets (e.g., chocolate, candies, black sugar, hot chocolate, or cookies) (Chou et al., 2008) to relieve discomfort.

Heavy, lengthy, or irregular periods. According to some studies (Krassas, et al., 1999; Weeks & Prentice, 2000), menorrhagia is associated with obesity and thyroid dysfunction, which are more prevalent in females with Down syndrome. In this literature, three studies (Ditchfield & Burns, 2004; Mason & Cunningham, 2008; Rodgers et al., 2006) have observed that menorrhagia appeared to be a particular problem in their sample of females with developmental disabilities, in terms of prevalence (Ditchfield & Burns, 2004) and management (Rodgers et al., 2006).

The results of a large postal survey by Rodgers et al. (2006) reported that 30% of

females with intellectual disability had suffered from heavy periods in the past 6 months. Mason et al. (2008) reported 23% of the participants disclosed heavy periods. Ditchfield and Burns (2004) stated that 81.8% of females with learning disability complained of menorrhagia. The percentage is very high compared with the other two studies because the number of participants is smaller (11 participants) than the other two (452 and 59 participants). It must be noted that this figure relates to the number of the participants who spontaneously mentioned this during the interviews.

Another problem besides the heavy periods was lengthy or irregular periods according to the studies. Rodgers et al. (2006) reported that 27% of the participants had experienced irregular periods and only 8% of them had experienced lengthy periods. Mason and Cunningham (2008) reported 14% were described as having had irregular periods in the past; however, the length of cycles was not presented as a discernible pattern in this study. Finally, one study (Carlson & Wilson, 1996) reported 12.7% of participants complained about all of the three problems (heavy, length, and irregular period).

Inappropriate behavior and mood changes. It may not be surprising that the combination of pain and heavy or lengthy periods has a significant impact on females' mood and well-being (Ditchfield & Burns, 2004). According to Quint, Elkins, and Kope (1999), cyclical behavioral changes are a common issue for females with developmental disabilities.

As shown in Table 2 above, three studies reported the number of participants who had experienced mood change (Chou et al., 2008; Ditchfield & Burns, 2004; Rodgers, Lipscombe, & Santer, 2006). The findings indicated that the percentage ranged from 16.7% to 72.7%. In the study by Ditchfield and Burns (2004, p.28), some descriptive statements were included: "I cry and am always in a bad mood," "I take it out on everyone," and "I'm moody and snap at people."

Two studies (Carlson & Wilson, 1994; Rodgers et al., 2006) also showed that the bad

mood impacted their behaviors. Carlson and Wilson (1994) reported 16.7% of the participants presented inappropriate behaviors such as smearing menstrual fluid or removing pads. Interestingly, those participants had not received any menstrual preparation. Rodgers et al. (2006) indicated 15% of the participants had presented inappropriate behavior, for example, mood and aggression (not usually described in detail), talking about menstruation in public, and problems with the use and disposal or apparent dislike of wearing pads.

Negative reactions. All the emotional and physiological problems stated above seem to be extremely negative experiences for the participants. Accordingly, attitudes of females with learning disabilities on menstruation were overwhelmingly negative (Ditchfield & Burns, 2004). They described it as a difficult and distressing event. Carlson and Wilson (1994) reported that 41.7% of the participants reacted negatively when they menstruated. Chou et al. (2008) also stated that many participants replied they had negative feelings about menstruation, such as the result of premenstrual symptoms problems, menstrual care work, or the use of inefficient pads. Carlson and Wilson (1994), additionally, stated that 40% of the participants overcame negative reactions by, for example, seeing a sister's or mother's menstruation, and arranging for the young females with DD to observe peers at school changing their menstrual pads.

Hygiene problems. Menstrual hygiene issues are a common point of discussion with teens with DD and their families (Dizon, Allen, & Ornstein, 2005). Despite concerns raised in the literature about "hygiene" difficulties resulting from menstruation, Carlson and Wilson (1994) reported that there were no mothers who reported experiences with such difficulties. On the other hand, another study (Rodgers et al., 2006) reported several hygiene problems such as blood-stained clothes (50%). Carlson and Wilson (1996) found that 22.2% of participants had blood stained clothes or hands.

Hygiene problems may be closely related to self-care skills; therefore, appropriate

self-care training for females with developmental disabilities is necessary in order to prevent hygiene difficulties. To teach the self-care skills, it may be necessary to identify what types of self-care problems the females with developmental disabilities have struggled with.

Self-care. The meaning of 'self-care' implies every aspect relating to menstruation including purchasing sanitary items and washing soiled clothing, or it might just include the aspect of changing a pad independently. Every study conducted surveys and interviews about self-care from a different point of view; therefore, the results of self-care are not identical among studies. In this literature review, only four studies (Carlson & Wilson, 1994; Chou et al., 2008; Mason & Cunningham, 2008; Rodgers & Lipscombe, 2005) indicated the levels (well, medium, and low) of self-care. Due to the different definitions of self-care in each study, the percentages of each level may not be comparable among studies.

Table 2 above presents the specific information of the results in self-care. Carlson and Wilson (1994) reported 54.1% of participants were dependent (low level) for the entire pad changing process. 37.5% of participants were partly independent (medium level) and 8.3% of participants were completely independent (high level). Chou et al. (2008) reported that only 3.6% of the participants obtained, changed, and disposed of menstrual pads fully dependently. The percentage of people who did menstrual management with some amount of help from caretakers was 30.9 and 26% of the participants did it independently. The rest of the participants (18.2%) seemed not to respond to this question although the authors of this study did not specify that. Mason and Cunningham (2008) found 15 females (26%) with Down syndrome were able to manage menstruation care themselves with occasional reminding unless they were tired, upset, or ill. Fourteen participants (24%) were described the level of self-care as problematic, and four participants (7%) needed complete care.

Rodgers and Lipscombe (2005) presented five different tasks (e.g., identify start of period, manage to keep clean during period, obtain pads/tampons, change pads/tampons, and

dispose of pads/tampons) of the self-care at three different levels (e.g., females independently, females with help, and caretakers). Each participant may not be in the same level for each task; for example, some participants who identify that their period has started may not change their pads/tampons). As a result, the total number for each task is different; therefore, all the tasks were not averaged. Table 2 illustrates all percentages and number of participants across the five tasks.

Due to measuring different tasks of menstrual self-care skills in each study, the results that four studies reported may not be averaged and generalized. Nevertheless, this result should focus on the identification of the individuals' independent level and make available appropriate supports for them in accordance with the identified results.

Other problems. There were additional problems stated in only three studies. Chou et al. (2008) reported that 22.8% of the participants had experience with abdominal swelling and breast swelling and 14.3% felt severe headaches or were dizzy. Another 7.1% of participants reported that they had no desire to eat or move when they menstruated. Rodgers et al. (2006) stated several other problems such as feeling unwell or tired (43%), increased seizures (26%), sleep disturbance (17%), and any other problem (14%) such as digestive problems, headaches, anemia, and weight gain as a result of hormonal contraception. Ditchfield (2004, p.28) also stated that 72.73% of the participants described that some symptoms had a major impact on their lives, such as becoming "hot and sick," "having black outs," and "being as cold as ice."

Communication between Females with DD and Mothers or Caretakers to Manage Menarche and Menstruation

According to Rodgers et al. (2006), in western cultures, menstruation is discussed openly in only limited circumstances even though communication is important in relation to menstruation. Even though communication is a critical factor to request any support with

menstruation difficulties, it is necessary to align with additional training or support on how to communicate needs in keeping with social norms (e.g., alphabet/phrase board, specific sounds, minimal speech, or gesture). According to Rodgers et al. (2006), 46% (*n* = 188) of females did not let their caretakers know that periods were a problem for them, including 57% (*n* = 107) of those who could speak clearly and were easily understood. Saltonstall (2007) reported that only one of four mothers of females with cognitive delay recalled communicating with her daughter about menstruation or related topics prior to menarche (e.g., what her period would look and feel like). The perceptions of daughters' comprehension abilities and the daughters' reactions to the actual event of menarche limited the other three mothers' communication about menstruation.

Systems of Support during the Transition to Menarche

Preparation. Today most of young females are prepared for menstruation. It is suggested that preparation begins early so that menstruation can be normal part of the life (Gomez, Calson, & Dooren, 2012). Specific preparation for the young female with an intellectual disability should begin around 9 years of age since each individual begins the first menstruation at a various age (Burke, Kalpakjian, Smith, & Quint, 2010). A more positive attitude toward menstruation can be achieved if girls are physically and emotionally prepared (Shainess, 1961). Another study (Beausang & Razor, 2000) reported that females and girls who described having received insufficient or negative preparation for the transition reported some of the most negative experiences with menarche and menstruation. This result indicates the importance and necessity of the preparation during the transition to menarche. A few researchers (Burke, Kalpakjian, Smith, & Quint, 2010; Gray & Jilich, 1990) suggested the preparation before menarche for females who have a disability, and her family members.

As shown in Table 2, Carlson and Wilson (1994) reported 37.5% of participants received some preparation before menarche which included one or more of the following:

explanation and reassurance; seeing another member of family menstruating; practice at pad wearing and pad changing. Nevertheless, all of the mothers recalled feeling that they had not been adequately prepared for their own menarche as maturing girls. Dominant feelings associated with the daughter's transition to menstruation included responsibility, uncertainty, and worry**.** In another study by Carlson and Wilson (1996), 20.4% of the caretakers of females with intellectual disability reported involvement in menstrual preparation. In the Saltonstall's study (2007), two of four mothers (50%) of the participants anticipated their daughter's menarche prior to occurrence through menstrual knowledge, past experience, and observation of physical development. One mother took her to a hospital as her preparation action, and they offered a class for girls. Yet, it did not go well due to her delays, according to the mother. Another mother prepared materials and initiated discussion of the impending event with both her husband and the array of service providers involved in her daughter's development. Mason and Cunningham (2008) reported that 8% of mothers of females with Down syndrome were not prepared for their daughter's menarche. Some of them assumed that girls with Down syndrome mature later compared with the general population. In the Ditchfield's study (2004), none of 11 participants felt that they had been prepared for the onset of the menarche.

Overall, four out of 10 studies indicated that mothers or caretakers prepared females with developmental disabilities for menarche and menstruation. This result strongly suggests a need for more help with caretakers of females with DD.

Teaching menstrual care. Some negative factors, such as an uncertainty about how much these young females can understand, the relatively low priority given to independence (Hammar & Barnard, 1966), and the stress and anxiety of an increasing burden of physical care (Adams, Wilgosh, & Sobsey, 1990) may affect parents' acceptance of menstrual skill development. Nevertheless, mothers or caretakers in the three studies (Carlson & Wilson,

1994; Rodgers & Lipscombe, 2005; Saltonstall, 2007) tried to teach menstrual management skills to females with developmental disabilities.

Carlson and Wilson (1994) indicated that 50% of mothers of females with a learning disability tried to teach menstrual pad changing skills, either before or after menarche and 66.7% of mothers felt that they had been successful. Rodgers and Lipscombe (2005) found that for 29%of the females, respondents reported that no one had ever tried to teach them to manage their own menstrual care. It might be assumed that it was the females with more profound disabilities whom no one tried to teach. Also, they stated that for females with a high or medium level of independence it was significantly more likely that someone had tried to teach them to manage their own menstrual care than for those with a low level of independence. According to Saltonstall (2007), three of four mothers tried to teach how to use menstrual supplies. Only one of them expressed her daughter's accomplishment of progress in a positive way, for example, "she's doing really well."

Effectiveness of the Supports

Meaningful lifestyle changes are possible only if the newly acquired skills are performed across the full range of situations the learner typically encounters, and are performed in appropriate situations for an extended length of time (Epps, Stern, & Horner, 1990). To do so, adequate supports should be available for caretakers or females with DD.

Carlson and Wilson (1994) indicated that some mothers received assistance from others, such as a teacher and doctor, in overcoming their daughters' negative reactions to menstruation. Others received menstrual skill development support from teachers and respite staff and gathered preparation ideas through school staff. Carlson and Wilson (1996) reported that some participants (caretakers) had accessed information relevant to menstrual management for females who have disabilities during their pre-service training, through workshops or formal discussions, reading, personal experiences, or incidental conversations.

However, the content and comprehensiveness of the information accessed was not clear and some participants reported that this information had not been detailed. Ditchfield and Burns (2004) reported that participants were isolated to a certain extent by the difficulties they were experiencing. They did not feel that they had had appropriate supports for their menstruation management. They described menstruation management as a "problem." In addition, the mothers in the Saltonstall's study (2007) stated that they had not been able to access resources that they felt were appropriate to their unique mothering context.

Because people expect that females will manage their own menstrual care and there is a stigmatization associated with stained clothing, instruction on menstrual hygiene for females with DD is of paramount importance (Epps et al., 1990). In this literature, a majority of studies (eight studies) used interviews or surveys while three studies (Epps et al., 1990; Griffin et al., 1994; Klett & Turan, 2012) conducted a different method, a single subject design and a case study.

Another study by Griffin et al. (1994) conducted a case study for each of six females who had an intellectual disability. This study developed a model of intervention to assist with menstrual management for females with high support needs. The key areas of intervention are the following: (a) assessment of the females' actual or potential menstrual management skills; (b) increasing awareness of attitudes towards menstruation for females who have intellectual disability, among people assisting them; and (c) provision of a range of information, processes and resources to assist educators, families, and others providing personal assistance, with informed menstrual management for these females. The results of this study indicated positive gains made by four of six participants.

Preferred Types of Supports or Needs

To gain successful outcomes, menstrual care should be provided by people who have positive supportive attitudes. Increasing awareness of the range of possible feelings about

menstruation, and encouragement of menstrual acceptance among those providing personal assistance, may be essential factors in menstrual management for females with developmental disabilities (Gray & Jilich, 1990).

Ditchfield (2004) found that all participants said they desired more information, but no specific needs were stated; however, three other studies (Carlson & Wilson, 1996; Griffin, Carlson, Taylor, & Wilson, 1994; Saltonstall, 2007) indicated specific preferred suggestions for menstruation. Carlson and Wilson (1996) stated that 94% (n = 59) of the participants (caretakers) suggested that information and resources should be more readily available. Moreover, 78% (n =38) of them indicated that they would like more advice or practical support about menstrual management for the females with whom they work. The results in the Saltonstall's study (2007) suggested that mothers preferred schools and medical offices for accessing social and educational support about menstruation. The available services and supports could be (a) anticipation and preparation for menarche, (b) strategies for supporting self-care during menstruation, (c) opportunities for parents of maturing students with disability to connect with one another, and (d) issues related to fertility and safety. Finally, the literature review by Griffin et al. (1994) suggested that a menstrual management model needs to take account of three factors: (a) the attitudes of people giving young females with high support needs assistance; (b) an awareness that these females have the potential to learn and retain menstrual management skills; and (c) that the most appropriate model of assessing initial menstrual skill levels may be via interviews with people familiar with the females.

One study in Taiwan (Chou & Lu, 2012) reported a different point of view. All 12 mothers had never accessed information regarding menstrual management. However, most mothers did not feel they needed the information, training, or assistance related to the menstruation from public services. The reason was they thought their daughters were severely disables and needed special care. They thought that no one could help their

daughters.

As the studies suggested above, further information and supports in various ways are necessary in terms of the needs of females with developmental disabilities. In addition, the High Court of Australia (1992) reported that there was an increasing need for therapists, families, educators, and residential staff to assist females who have high support needs to manage their menstruation via educational and lifestyle approaches.

Current Available Supports or Resources

A variety of supports or resources exist both on-line and off-line even though most of them have not been published formally. Nevertheless, they may play an essential role to support females with developmental disabilities or caretakers. The examples of support centers (websites), interventions, and tools are described below.

The website of the Center for Developmental Disability Health Victoria (CDDH) in Australia provides abundant products and resources for health care issues for individuals with DD. The Center has produced two booklets to support females with disabilities in managing their menstruation. One is targeted to medical practitioners and the other to help workers. In addition, a training video, *Janet's Got Her Period*™ (Gray & Jilich, 1990) is available to teach menstrual self-care to young females with severe developmental disabilities, although it may not be affordable for every individual with DD due to the high cost. This training video includes (a) 17-minute video in two versions demonstrating menstrual self-care, (b) illustrated storybook with full-color photographs, (c) extensive resource book for teacher, parents, and caregiver, (d) computer pictograph wall chart outlining the steps for changing a sanitary pad , and (e) 24 laminated cards for student use.

The New South Wales Council for Intellectual Disability (NSW) in Australia posted information about “managing menstruation” in 2011. This information includes (a) Key facts of managing menstruation for females with an intellectual disability (ID), (b) Assisting

females to manage their periods, (c) Problems with periods, (d) Role of the general practitioner, (e) Treatments for problem periods, (f) Operation to stop periods. The information provides brief explanations for each topic; therefore, caretakers of females with ID will need further help.

The website of AboutKidsHealth (2013), the world's leading non-profit information source for children's health, provided a guide of "Menstruation and Mental Disability: Advice for Parents of Adolescent Girls." The guide described how to help girls with an intellectual disability to cope with menstruation and some suggestions for helping girls (e.g., use calendar, writing down the symptoms during the period, doing exercise and physical activity, pads are cheaper than diapers, and so on).

The Florida Developmental Disabilities Council developed a guide book titled *Sexuality Education for Children and Adolescents with Developmental Disabilities* (Baxley & Zendell, 2005) for parents or caregivers of individuals with DD. In this book, menstrual management is not the major topic, but useful resources and information were provided with pictures, and tips for parents or caretakers so that they prepare and apply skills to the young females with DD.

In addition**,** Sorensen-Burnworth and Bing (2008) presented their study on menstruation training an adolescent with autism at the Association for Behavior Analysis International Symposium. The presentation described and reviewed a skills training program for menstruation training for a young adolescent with autism living at home. In preparation for menstruation, a skills training protocol consisting of a social story and positive practice were utilized to teach the necessary skills for independent use of sanitary napkins. Task analysis data demonstrate acquisition of the skills. When the adolescent began menstruation, skills were successfully generalized. The result indicated the importance of preparation and skill training prior to menstruation.

Although the resources illustrated as well as many others have been available both on-line and off-line, their efficacy with analyzed data has not been established as evidence. This is the case for many commercially available products offered by various companies. The price range of the resources is varied from free to quite expensive.

The literature review indicates that the types of study methods in the literature during the last 20 years have changed in accordance with the social-cultural and legal movement of the time (Saltonstoll, 2009). This means that more studies should be conducted with sophisticatedly analyzed issues and needs for menstrual management care. Furthermore, the studies should be designed to support the needs of contemporary females with developmental disabilities.

CHAPTER 3

Methods and Procedures

The purpose of this study was to investigate menstrual problems and issues of parents or caretakers of females with developmental disabilities (DD) using a survey and a follow-up interview with parents or caretakers. The survey included a demographic profile and the unpublished Menstrual Management Questionnaire for Parents/Caretakers (MMQ-P/C) (Park, 2011). They were conducted by online survey via SurveyMonkey™. For the interview study, telephone interviews were conducted with 10 questions. This chapter describes (a) participants, (b) instruments, (c) study design, and (d) data analysis.

Participants

Participants for the survey study. Participants of the parents or caretakers of females with DD completed the survey. The researcher conducted on-line search for local, national, and international organizations related to DD and contacted them by email. The email included the purpose of the study and approval document from University of Kansas Human Subjects Committee—Lawrence (HSCL) (Appendix A). As soon as responses from the organizations were received, the announcement letter with a survey link (Appendix B) for the study was sent to the responding organizations so that they could distribute the letter and survey link. The organizations posted the announcement letter with a survey link on their websites, Facebook pages, or distributed the survey link for the parents' groups by email.

Sampling procedures for the survey study. The researcher searched and found 93 organizations that provide resources to families of individuals with DD across the states (local and national-wide). Upon approval from each of the organizations from the initial email contact, the researcher followed up by email with a brief reader-friendly announcement letter about the study and a link to the survey (Appendix C).

These organizations were selected purposely because of their local and national-wide

membership of families interested in issues related to DD. This allowed this study to attempt to obtain a representative sample of the families of females with DD that is associated with a local or national organization for families of persons with DD with regards to geographical distribution and socioeconomic distribution.

Twenty organizations of the 93 contacted responded as willing to post the survey link on their websites or to distribute the survey link to the parents' groups by email; 18 of them allowed for posting the survey link on their Facebook pages. The responses of the survey were from 20 different states (California, Coronado, Illinois, Iowa, Kansas, Massachusetts, Michigan, Mississippi, Missouri, Nebraska, New York, North Dakota, Ohio, Oklahoma, South Carolina, Tennessee, Texas, Utah, Washington, and Washington D.C.) and one foreign country United Kingdom. A total of 61 participants (parents or caretakers of females with DD) completed the survey via SurveyMonkey™.

Participants for the interview study. In order to obtain volunteers for the interview study, the volunteer agreement form (Appendix D) was provided at the end of the survey. This form obtained contact information, email address or telephone number from volunteers.

Participant selection procedures for the interview study. As stated above, at the end of the online survey, participants were asked to indicate their willingness to volunteer for an interview by completing the volunteer agreement statement. With their agreement to volunteer, they were asked also to provide contact information (e.g., email address and/or telephone number). Forty two survey participants agreed to volunteer for the interview and all of them left their email addresses and/or their phone numbers. As soon as the survey link closed, the researcher contacted the participants by email and explained about the interview, its confidentiality procedures, and preferred date and time. Once the interview time set up, the interview consent form (Appendix F) was sent to the participants by email. The five participants out of the 43 volunteers were randomly selected to be interviewed.

Participant criteria. Participants of this study met the following eligibility criteria. They (1) identified themselves as parents or caretakers of females with DD before or after menarche (first menstruation), (2) were able to read and write English on a computer, and (3) had access to the Internet and telephone.

Demographic Profile

Participant characteristics of the survey study. The 61 volunteer participants for the survey study were asked 17 questions (Appendix E) about their age range, gender, current resident area, ethnicity, education level, employment status, and marital status. Table 3 shows the demographic information of the survey respondents.

Table 3

Participants' Characteristics for the Survey Study (*N* = 61)

Variable	*n / M*	% / *SD*
Relationship		
Caretaker	5	8.2%
Legal guardian	2	3.3%
Parent	53	86.9%
Sibling	1	1.6%
Missing	0	0.0%
Gender		
Female	60	98.4%
Male	1	1.6%
Missing	0	0.0%
Age		
21-29	1	1.6%
30-39	7	11.5%
40-49	28	45.9%
50-59	21	34.4%
60+	4	6.6%
Missing	0	0.0%
Race		
African American	0	0.0%
White	59	96.7%
Hispanic	1	1.6%
Pacific Islander or Native Hawaiian	1	1.6%
Missing	0	0.0%
Marital status		
Divorced	10	16.4%
Married	47	77.0%
Separated	2	3.3%
Single	2	3.3%
Missing	0	0.0%
Education level		
High school or vocational school diploma	11	18.0%
Bachelor's degree	25	41.0%
Master's degree	13	21.3%
Doctorate degree	4	6.6%
Associate degree	8	13.1%
Missing	0	0.0%
Employment		
Employed outside the home	37	60.7%
Working at home	6	9.8%
Housewife/Husband	14	23.0%
Unemployed	4	6.6%
Missing	0	0.0%

Participant characteristics for the interview study. The characteristics of the interview participants were acquired from the demographic information of the survey study. As the sampling procedures of the interview study (p. 39) described, the participants who were willing to volunteer for an interview left their email addresses. The researcher of this study contacted all volunteers by email for demographic information. Thus the demographic information available for all volunteers for the survey was on email files for those selected for the interview. See Table 4 for the specific demographic information of the interview participants.

Table 4

Participants' Characteristics for the Interview Study (*N* = 5)

Variable	Participant A	Participant B	Participant C	Participant D	Participant E
State	Kansas	Nebraska	Missouri	Washington	Kansas
Age range	40-49	40-49	40-49	30-39	40-49
Race	White	White	White	White	White
Marital status	Married	Married	Married	Married	Married
Education level	Associate degree	Bachelor's degree	High school	Bachelor's degree	Bachelor's degree
Employment	Housewife	Employed	Employed	Employed	Employed

Instruments

Both quantitative and qualitative instruments were utilized in this study. Two quantitative instruments included a demographic profile and unpublished Menstrual Management Questionnaire for Parents/Caretakers (MMQ-P/C) (Park, 2011). The qualitative instrument was a semi-structured interview that was administered to the study participants who indicated a willingness to participate.

Quantitative instruments. A demographic profile and MMQ-P/C (Park, 2011) were administered to the study participants via an online survey using SurveyMonkey™. The descriptions of the demographic profile and MMQ-P/C are stated below.

Demographic profile. Participants were asked 17 questions (Appendix F) about their age range, gender, current resident area, ethnicity, education level, employment status, and marital status. They were asked to provide the following information about females with DD: age (date of birth), type of disability, level of disability, ability of communication, regularity of the menstrual cycle, and medical treatment information. The collected information was used to describe the demographic characteristics of the participants of the study. The level of disabilities included mild, moderate, severe, and profound.

Menstrual Management Questionnaire for Parents/Caretakers (MMQ-P/C).The MMQ-P/C (Park, 2011), which was developed specifically for use in this study, has three parts. The first section consisted of six questions related to the degree of independence of the females' menstrual care. All the six questions used a 6-point Likert scale ranging from 0 (*Never*) to 5 (*Always*) and *Do not Know*. Example questions are "She identifies and communicates (verbally or gestures) that her period has started." and "She changes pads/tampons during her period independently (does not require assistance)."

The second part consisted of seven questions related to teaching and support for the female's menstrual management. All the seven questions used a 6-point Likert scale ranging from 0 (*strongly disagree*) to 5 (*strongly agree*) and *not Applicable*. Example questions are "I tried to teach or communicate with the female about period (menstrual) management skills before her first period." and "My teaching or communication was successful to make the female understand period (menstrual) management skills."

Finally, the last part consisted of six questions related to accessibility of information or resources about menstrual management. Two of the questions used a rank order from 1 (*most preferred*) to 10 (*least preferred*). The other four questions used a 6-point Likert scale ranging from 0 (*Strongly Disagree*) to 5 (*Strongly Agree*) and *Not Applicable*. An example question for the rank ordering of resource accessibility is "Please write a number next to the

10 resources below to show your preference for preparation of the female's first period (menarche)." An example of the Likert-scale questions is "It was easy to find information or resources for the female's period (menstrual) management after her first period."

The MMQ-P/C (Park, 2011) was primarily for use with parents or caretakers of females with DD who have already started their first menstruation. However, this questionnaire was also administered to the parents or caretakers whose females with DD have not started their first menstruation. Accordingly, the instruction included the following sentence: "If your daughter (female) has not started her first period, please imagine your future and answer the questions."

Qualitative instrument. In addition to the online survey, a semi-structured interview was administered to five participants in order to obtain additional and in-depth information. Ten interview questions were developed for the interview study.

Interview questions. In order to obtain adequate interview data related to the research questions, the following 10 questions were developed as a guide for the interview:

1. How did you identify when your daughter's period started?
2. What thoughts and feelings about your daughter's first period did you have?
3. What did you do to help your daughter's first period?
4. How did you communicate with your daughter to manage her period?
5. What kind of educational approaches for your daughter have you considered? Why?
6. Do you believe the educational approaches are necessary for your daughter? Why?
7. What support systems did you have access to during the transition to your daughter's first period?
8. How were those supports helpful?
9. What types of support are preferred? Or what types of supports do you wish you had had?

10. If you were to give advice to other parents what would the advice be?

Study Design for the Survey Study

The present study used a cross-sectional design where a sample was obtained to examine the menstruation-related issues among parents and caretakers of females with DD.

Statistical analysis. The participants' responses to the on-line survey were coded into a database and then coding accuracy was double-checked. Descriptive statistics such as means and standard deviations (for continuous data) and frequencies, proportions, and cross-tabulations (for categorical data) were calculated to describe the socio-demographic characteristics of the study sample. Next, reliability of the instruments was assessed by Cronbach's coefficient alpha to indicate the extent to which the items of scales are interrelated with each other (i.e., internal consistency). Finally, bivariate tests (Wilcoxon-Mann-Whitney test, correlation) were conducted to examine the study hypotheses. Prior to analyses, outliers and assumptions of normality, variance homogeneity, linearity, and/or homoscedasticity were checked and properly handled as needed. Statistical significance was determined at a nominal alpha level and all analyses were conducted using SAS 9.3 (SAS Institute, 2002–2010).

Study Design for the Interview Study

This study used a semi-structured interviews protocol. Although semi-structured interviews involve the use of pre-identified topics and questions, the interviewer had freedom to change the wording and sequence of the pre-developed questions during the interviews (Kvale, 1996; Robson, 1993). According to Morse and Field (1995), semi-structured interviews are appropriate when the researcher knows what questions to ask but does not know how the participants will respond. Due to these reasons, a semi-structured interview was selected for this study. The interview was conducted in order to enhance the results of the quantitative survey study.

Each interview was by telephone. All the interviews were recorded using audio recordings, transcribed into Microsoft Office Word ™ documents with the participant's name and the date of the interview conducted, and stored in a secure online storage file (Dropbox™) which was named "Transcripts of the Interview Study." Each interview ranged from 10–25 minutes in length.

Data analysis. Qualitative research should be manageable for data collection and analytic procedures (Merriam, 1998). To make the process manageable, the data analysis procedures for this study followed some parts of what Stringer (2004) recommended. The procedures were (a) reviewing the collected data, (b) unitizing the data, (c) categorizing and coding, (e) organizing a category system, and (f) interpretation.

Reviewing the collected data. In order to become familiar with the contents of the research, researchers should review transcripts of interviews as much as possible (Marshall & Rossman, 2006). There were five interview transcripts for this study. The researcher reviewed the transcripts numerous times.

Unitizing the data. To identify the main ideas and concepts from the transcripts, the discrete elements were blocked out from the transcripts. For this procedure, Microsoft Office Word™ was used. Literally, the elements that were related to the main ideas and concepts (mostly, sentences and phrases) were cut out and pasted to the new document which was labeled "Main Items."

Categorizing and coding. Based on the research questions for the interview study, three categories (issues and effects, communication, and supports or recourses) and five subcategories (negative reactions, problems experienced, preparation, supports or resources received, and supports or resources wanted by parents) were developed. Once the data had been unitized, the participants were coded in an Alphabetic order (A though E), and the elements related to the categories were sorted and coded with eight different colors and

numbers in accordance with the categories and subcategories. For example, the code “A1” colored by yellow meant the first sentence or paragraph was from the first participant under the “issues and effects.”

Organizing a category system. A new Word document which was named “Coding” was created and this contained three categories and five subcategories. All the coded units were listed under each category and subcategory so that they could be interpreted in the results. Also, the participants’ demographic information with coding (A through E) was added into this “Coding” document because this information could be a good source for interpreting the data.

Interpretation. The purpose of the interview study was to enhance the interpretation of the results from the survey study (quantitative results). Therefore, the interview study simply summarized or quoted the organized coded sentences and paragraphs under each category and subcategory while considering the participants’ characteristics (both mothers and their daughters with DD).

CHAPTER 4

Results

The purpose of this study was to investigate the kinds of help or support that were needed or received for parents or caretakers of females with developmental disabilities (DD) to manage menstrual care. In this study, an online survey and follow-up interviews were completed by parents or caretakers of females with DD. The data was analyzed to address the research questions for both the survey study and the interview study.

Results Related to the Survey Study

Characteristics of parents and caretakers. According to Table 3 (see p. 41), the respondents to the survey were the parents or caretakers of females with DD. The majority of the parents or caretakers were female (*n* = 60, 98.4%), non-Hispanic White (*n* = 59, 96.7%), married (*n* = 47, 77.0%), and employed (*n* = 37, 60.7%). About one-third were 40–49 years old (*n* = 28, 34.4%), and about 60% had a bachelor's degree or higher.

Characteristics of females with DD. Table 5 presents the descriptive statistics of socio-demographic variables for the females with DD. On average, the females with DD were 16.93 years old (*SD* = 7.25). The majority of the females had autism spectrum disorder (*n* = 24, 39.3%) followed by intellectual disability (*n* = 16, 26.2%), Down syndrome (*n* = 15, 24.6%), or blindness or cerebral palsy (*n* = 6, 9.8%).

Table 5 also described the females' period information. Forty eight (78.7%) out of 61 females already had their first period. About half of them (*n* = 28, 58.3%) had regular period cycles in the past six months. All 48 females used tampons and/or pads during their periods for hygienic protection. The majority of them (*n* = 47, 97.9%) preferred using pads rather than tampons (*n* = 4, 8.3%). Three of them used both tampons and pads. The majority of the 48 females (*n* = 29, 60.4%) did not have related medical treatments (medication, sterilization surgery, and so on). Some of the parents/caretakers who had medical treatments for their

females with DD reported that they used birth control pills, oral contraceptive, and Implanon.

Table 5

Characteristics of Females with DD (N = 61)

Variable	*n* / *M*	% / *SD*
Disabilities		
Autism spectrum disorders (ASD)	24	39.3%
Blindness	1	1.6%
Cerebral palsy	5	8.2%
Down syndrome	15	24.6%
Intellectual disability	16	26.2%
Missing	0	0.0%
Female's age	17.87	7.90
First period		
Yes	48	78.7%
No	13	21.3%
Missing	0	0.0%
Regular cycle		
Yes	28	58.3%
No	18	37.5%
Missing	2	4.2%
Protection		
Yes	48	100.0%
No	0	0.0%
Missing	0	0.0%
Protection tool*		
Tampons	4	8.3%
Pads	47	97.9%
Tampons & Pads	3	6.3%
Medical treatment		
Yes	19	39.6%
No	29	60.4%
Missing	0	0.0%

*Multiple responses were allowed.

Socio-demographic characteristics of participants. As Table 6 shows, the socio-demographic characteristics did not differ between the females with mild or moderate DD (M/M group) and those with severe or profound DD (S/P group) and between their parents or caretakers. (Fisher's exact probability = .01–.54, *p*'s = .26–1.00, Cramér's *V*'s =0.11–0.22;

females' age: t [59] = 0.66, p = .66, Cohen's d = 0.51), except for type of disability. Most of the M/M group had autism spectrum disorder (n = 15, 33.3%), Down syndrome (n = 15, 33.3%), or intellectual disability (n = 12, 26.7%), while the majority of S/P group had autism spectrum disorder (n = 9, 56.3%) followed by intellectual disability (n = 4, 25.0%) and cerebral palsy (n = 3, 18.8%) (Fisher's exact probability = .00, $p < .05$, V = 0.41). See Table 6 for more details.

Table 6

Socio-demographic Characteristics between Two Groups of Females with DD

	Group 1 (Mild or moderate) (*N* = 45)		Group 2 (Severe or profound) (*N* = 16)				
Variable	*n* / *M*	% / *SD*	*n* / *M*	% / *SD*	Fisher / *t*	*p*	ES
Relationship					0.08	.61	0.16
Caretaker	3	6.7%	2	12.5%			
Legal guardian	1	2.2%	1	6.3%			
Parent	40	88.9%	13	81.3%			
Sibling	1	2.2%	0	0.0%			
Missing	0	0.0%	0	0.0%			
Gender					0.26	.26	0.22
Female	45	100.0%	15	93.8%			
Male	0	0.0%	1	6.3%			
Missing	0	0.0%	0	0.0%			
Age					0.01	.66	0.22
21-29	1	2.2%	0	0.0%			
30-39	4	8.9%	3	18.8%			
40-49	20	44.4%	8	50.0%			
50-59	16	35.6%	5	31.3%			
60+	4	8.9%	0	0.0%			
Missing	0	0.0%	0	0.0%			

Table 6

Socio-demographic Characteristics between Two Groups of Females with DD (Continued)

Variable	Group 1 (Mild or moderate) (*N* = 45)		Group 2 (Severe or profound) (*N* = 16)		Fisher / *t*	*p*	ES
	n / *M*	% / *SD*	*n* / *M*	% / *SD*			
Race					0.54	1.00	0.11
African American	0	0.0%	0	0.0%			
White	43	95.6%	16	100.0%			
Hispanic	1	2.2%	0	0.0%			
Pacific Islander or Native Hawaiian	1	2.2%	0	0.0%			
Missing	0	0.0%	0	0.0%			
Marital status					0.06	.84	0.16
Divorced	8	17.8%	2	12.5%			
Married	34	75.6%	13	81.3%			
Separated	1	2.2%	1	6.3%			
Single	2	4.4%	0	0.0%			
Missing	0	0.0%	0	0.0%			
Education level					0.01	.73	0.18
High school or vocational school	8	17.8%	3	18.8%			
Bachelor's degree	18	40.0%	7	43.8%			
Master's degree	11	24.4%	2	12.5%			
Doctorate degree	2	4.4%	2	12.5%			
Associate degree	6	13.3%	2	12.5%			
Missing	0	0.0%	0	0.0%			

Table 6

Socio-demographic Characteristics between Two Groups of Females with DD (Continued)

	Group 1 (Mild or moderate) (*N* = 45)		Group 2 (Severe or profound) (*N* = 16)				
Variable	*n* / *M*	% / *SD*	*n* / *M*	% / *SD*	Fisher / *t*	*p*	ES
Employment					0.02	.77	0.15
Employed	26	57.8%	11	68.8%			
Working at home	4	8.9%	2	12.5%			
Housewife/Husband	12	26.7%	2	12.5%			
Unemployed	3	6.7%	1	6.3%			
Missing	0	0.0%	0	0.0%			
Disability					0.00	.01	0.41
Autism spectrum disorders (ASD)	15	33.3%	9	56.3%			
Blindness	1	2.2%	0	0.0%			
Cerebral palsy	2	4.4%	3	18.8%			
Down syndrome	15	33.3%	0	0.0%			
Intellectual disability	12	26.7%	4	25.0%			
Missing	0	0.0%	0	0.0%			
Female's age	17.87	7.90	16.40	6.82	0.66	.66	0.51

Scale Reliability and Assumption Checks. The reliability of the instruments was examined by Cronbach's coefficient alpha. The six items of the independence scale showed high internal consistency (α = .92) but internal consistency of the educational needs scale was not acceptable (α = .38). The participants' responses on individual items were standardized within each of two levels of DD classification (mild or moderate, severe or profound). No item was found to have univariate outliers with an absolute standardized score greater than 3.29 ($p < .001$). The oval-shaped bivariate plot indicated that the pairs of independence composite score (average of 6 items) and educational needs composite score (average of 7 items) were linearly related. However, homoscedasticity could not be assumed because the bivariate plot was not of the same width, with some bulging toward the middle. Also, the results of Shapiro-Wilk test for normality suggested that most of the items and both the composite scores did not follow a normal distribution within the two DD levels. Given the non-normal data and small sample size, two non-parametric tests, Wilcoxon-Mann-Whitney test and Spearman's rank-order correlations, were used to address the research questions.

Results for Research Question 1

Research Question 1: What are the levels and traits among females with DD in terms of degree of independence, educational needs, and information accessibility related to menstrual care?

Hypothesis 1: Females with mild or moderate DD are more independent in menstrual care than females with severe or profound DD.

Hypothesis 2: Parents or caretakers of females with mild or moderate DD seek more educational training or teaching for menstrual management compared to parents or caretakers of females with severe or profound DD.

Hypothesis 3: Parents or caretakers of females with mild or moderate DD seek more resources for menstrual management compared to parents or caretakers of females

with severe or profound DD.

Group differences were examined by the Wilcoxon-Mann-Whitney test that compared the medians between two levels of DD classification (mild or moderate: M/M group vs. severe or profound: S/P group), in terms of independence of the females with DD (Hypothesis 1), their parents' or caretakers' needs for educational training (Hypothesis 2), and resources (Hypothesis 3) related to menstrual management.

The M/M group showed significantly higher levels of independence compared to S/P group. Medians were significantly higher for the M/M group in each of the six independence items (z's = -4.36–-2.48, all p's < .05) as well as in the composite score (z = -4.07, p < .001) (see Table 7). Also, medians were significantly higher for the M/M group in three of the educational needs items (z's = -2.65–-2.06, all p's < .05) as well as in the composite score (z = -2.41, p < .05), suggesting higher level of educational needs for this group. There were no significant differences in "Ease to access for resources before and after menstruation" and "Helpfulness of the resources."

Results for Research Question 2

Research Question 2: Are there any associations between degree of independence, educational needs, and information accessibility and disability-related characteristics (type and severity), after controlling for parents' or caretakers' socio-demographic characteristics (e.g., age, ethnicity, marital status, education level, employment)?

Spearman's rank-order correlations were calculated in the overall sample between the independence composite score, educational needs composite score, "Ease to access for resources before and after menstruation," "Helpfulness of the resources," and severity of DD (1 = *mild*, 2 = *moderate*, 3 = *severe*, 4 = *profound*). Table 8 presents the correlation coefficients. Independence of the females with DD was positively associated with educational needs (r = .25, p < .05). Also, severity of DD was negatively associated with both the

independence (r = -.54, p < .001) and the educational needs (r = -.26, p < .05). Finally, "Helpfulness of the resources" was positively associated with "Ease to access for resources before menstruation" (r = .56, p < .001) and after menstruation (r = .61, p < .001).

Table 7

Mild & Moderate DD vs. Severe & Profound DD

	Group 1 (Mild or moderate) (N = 45)				Group 2 (Severe or profound) (N = 16)				*t*-test			WNW test	
Variable	*n*	*M*	*SD*	Med.	*n*	*M*	*SD*	Med.	*t*	*p*	*d*	*z*	*p*
Degree of independence													
Q1	23	3.09	0.90	3.00	12	1.42	0.90	1.00	5.21	.00	1.86	-3.87	.00
Q2	37	3.00	1.00	3.00	15	1.27	0.80	1.00	5.97	.00	1.83	-4.50	.00
Q3	43	1.44	0.73	1.00	15	1.00	0.00	1.00	3.95	.00	0.70	-2.48	.01
Q4	10	3.70	0.67	4.00	14	1.36	0.93	1.00	6.78	.00	2.81	4.00	.00
Q5	27	3.22	1.01	4.00	15	1.33	0.90	1.00	6.02	.00	1.94	-4.27	.00
Q6	26	3.19	0.98	3.00	14	1.29	0.73	1.00	6.38	.00	2.12	-4.36	.00
Average	43	2.60	0.80	2.83	15	1.33	0.69	1.00	5.45	.00	1.64	-4.07	.00
Educational needs													
Q1	19	3.53	0.90	4.00	5	2.60	0.89	2.00	2.04	.05	1.03	-2.06	.04
Q2	15	3.93	0.26	4.00	4	3.75	0.50	4.00	1.04	.32	0.56	-0.94	.35
Q3	29	3.38	0.86	4.00	7	2.43	0.98	2.00	2.56	.02	1.07	-2.34	.02
Q4	37	2.84	0.96	3.00	11	2.64	1.21	3.00	0.58	.57	0.20	-0.38	.71
Q5	38	2.13	1.04	3.00	9	1.11	0.78	1.00	2.75	.01	1.02	-2.65	.01
Q6	39	2.49	1.14	2.00	10	2.40	1.17	2.50	0.21	.83	0.08	-0.20	.84
Q7	25	3.08	1.00	3.00	6	3.17	0.75	3.00	-0.20	.84	0.09	-0.03	.98
Average	42	2.87	0.49	2.83	14	2.27	0.88	2.50	2.39	.03	0.97	-2.41	.02
Resources (before mens.)													
Teacher	35	5.94	3.32	6.00	14	5.50	3.18	5.00	0.43	.67	0.14	-0.31	.75
School nurse	34	5.06	3.27	5.00	11	4.18	2.82	4.00	0.80	.43	0.28	-0.63	.53
Doctor	31	4.42	2.96	4.00	13	2.92	3.09	1.00	1.51	.14	0.50	-1.85	.07
Nurse	30	4.63	2.09	5.00	11	3.09	1.76	2.00	2.17	.04	0.77	-2.20	.03
Internet	29	6.59	3.13	7.00	12	6.75	2.63	7.00	-0.16	.88	0.05	0.00	1.00

Table 7

Mild & Moderate DD vs. Severe & Profound DD (Continued)

	Group 1 (Mild or moderate) (N = 45)				Group 2 (Severe or profound) (N = 16)				*t*-test			WNW test	
Variable	*n*	*M*	*SD*	Med.	*n*	*M*	*SD*	Med.	*t*	*p*	*d*	*z*	*p*
Brochure	29	4.97	2.50	5.00	12	7.08	1.98	7.50	-2.61	.01	0.90	2.40	.02
Book	33	5.06	3.13	5.00	13	6.54	1.94	7.00	-1.58	.12	0.52	1.55	.12
DVD	28	6.00	2.23	7.00	14	6.21	3.04	7.00	-0.26	.80	0.08	0.51	.61
Conference/Workshop	30	5.97	2.97	6.50	13	6.62	2.06	7.00	-0.72	.48	0.24	0.48	.63
Support group	34	5.91	2.79	6.00	14	6.93	2.73	7.00	-1.15	.25	0.37	1.21	.23
Ease to access	39	3.23	1.31	3.00	13	2.69	1.11	3.00	1.33	.19	0.43	-1.27	.21
Resources (After mens.)													
Teacher	32	5.09	3.65	4.00	11	3.82	3.31	3.00	1.02	.31	0.36	-0.85	.40
School nurse	32	4.50	3.20	3.50	12	4.25	2.67	4.00	0.24	.81	0.08	0.08	.94
Doctor	32	4.59	3.08	4.00	15	3.53	3.29	2.00	1.08	.29	0.34	-1.41	.16
Nurse	29	4.17	2.05	4.00	11	3.18	1.72	3.00	1.42	.16	0.50	-1.42	.16
Internet	28	6.36	2.63	6.00	11	7.27	2.49	6.00	-0.99	.33	0.35	0.73	.47
Brochure	27	6.11	1.97	6.00	12	7.83	1.19	8.00	-2.80	.01	0.98	2.75	.01
Book	30	5.20	2.67	5.00	12	6.58	1.98	7.00	-1.62	.11	0.56	1.73	.08
DVD	28	6.25	2.15	7.00	12	6.83	2.29	7.00	-0.77	.45	0.27	0.67	.50
Conference/Workshop	30	6.83	2.72	8.00	11	7.64	2.01	8.00	-0.89	.38	0.32	0.70	.48
Support group	32	6.38	3.12	7.00	13	6.08	2.56	6.00	0.30	.76	0.10	-0.44	.66
Ease to access	37	3.27	1.19	3.00	11	2.55	1.13	3.00	1.79	.08	0.61	-1.65	.10
Helpfulness	38	3.63	0.88	4.00	11	3.18	0.98	3.00	1.45	.15	0.50	-1.41	.16

Note. *t*-test was conducted to compare the means of a continuous variable between two groups.
Med.: median. *d*: small = 0.2; medium = 0.5; large = 0.8.

Table 8

Correlation Coefficients

Variable	1	2	3	4	5	6
1. Degree of independence	1.00					
2. Education needs	0.25*	1.00				
3. Ease (before menstruation)	0.07	0.00	1.00			
4. Ease (after menstruation)	0.04	0.11	0.86**	1.00		
5. Helpful	0.12	-0.07	0.56**	0.61**	1.00	
6. Severity	-0.54**	-0.26*	0.01	-0.05	-0.10	1.00
N	70	69	64	58	61	61
M	2.30	2.72	3.16	3.17	3.62	1.92
SD	0.91	0.62	1.31	1.27	0.95	1.00

Note. Spearman's rank correlation coefficient (Spearman's rho) was calculated between two ordinal variables.
*$p < 0.05$, **$p < 0.01$.

Results Related to the Interview Study

Based on the research questions for the interview study, three categories were developed and each category included subcategories. The categories and subcategories are follows:

A. Issues of effects related to disabilities about experience of menstruation management

(a) Negative reactions

(b) Problems experienced

B. Parents/caretakers communication related to menstruation management

(a) Preparation for menarche (first period)

C. Supports or resources

(a) Supports or resources received

(b) Supports or resources wanted by parents

Characteristics of parents and caretakers. As Table 4 shows (see p. 42), the five participants randomly selected for the interview study lived in Kansas, Missouri, Nebraska, and Washington. All of them were mothers, married, and Caucasian. Their age range was 30–49 years. Most of mothers completed Bachelor's degree and were employed.

Characteristics of females with DD. Table 9 below describes the characteristics of the interview participants' daughters (females with DD). The females with DD were 11–27 years old and had Down syndrome, cerebral palsy, or autism spectrum disorders (ASD). The level of disability of the daughters with DD included mild (n = 3), moderate (n = 1), and severe (n = 1).

Table 9

Characteristics of Females with DD

Variable	Participant A	Participant B	Participant C	Participant D	Participant E
Daughter with DD					
Age	11	13	27	17	20
Disability	Down syndrome	Down Syndrome	Cerebral Palsy	Autism spectrum disorders	Autism spectrum disorders
Level of Disability	Mild	Moderate	Severe	Mild	Mild

Issues related to disabilities with experience of menstruation management.

Females with DD experience the same menstrual problems like any other females. However, parents or caretakers of females with DD experience more concerns or problems in terms of menstrual management issues such as communication, personal hygiene, inappropriate habits or behaviors, physical or mood changes, and so on (Gomez, Carlson, & Dooren, 2012). Most of the mothers in the interview study also expressed their negative feelings and problems related to menstrual management for their daughters with DD.

***Negative reactions*.** When the participants were asked how they felt when their daughters started the first menstruation, four participants said they were scared, anxious, worried, or nervous because of their daughters' disabilities. Two participants worried about their daughters' ability to express what they need and what they need to do when they have their period. Participant C and D worried about their daughters' personal hygiene during the period. Another issue that Participant D worried about was private versus public topics. She was wondering if her daughter speaks about it appropriately, like walking in to the classroom and saying "hey everyone, I've got my period!" This is a private topic, so she had lots of apprehension about how her daughter would actually handle it and follow up with it.

Participant B was the only one who did not show a negative reaction toward the first menstruation. She just stated that "I wished it hadn't come so soon." She said her daughter

did not have any problems with communicating with others. Since her daughter did not have communication problems, everything related to menstruation was transitioning well without concerns by explaining and talking about it.

> *It was scary because there is lot of hygiene involved. I was worried about how she would handle it and if she could actually, you know, change her pads during the day, and if the staff at school would be able to help her with that. There was lots of concerns about just general hygiene issues and also with her speaking about it appropriately, like walking in to the class room and saying "Hey everyone, I've got my period!" Really worried about, you know, private versus public topics. This is a private topic and if you have a problem you don't raise your hand in the middle of the class; you go up to the teacher and talk to her face to face quietly. So I have lots of apprehension about how she would actually handle it and follow up with it.* (Participant D)

Problems experienced. Participant A stated that her daughter is not good at communicating when she does not feel well; therefore, she was cranky when she had headaches or cramps when menstruating. Participant C also said that her daughter was crankier and fussier during her period. It seemed like her mood, action, and even appetite changed a lot. She responded as if she was very scared by her symptoms during menstruation. She stated that "Probably like her second and third months, she was getting a really bad cramp and she would really cry and so then, that's why I went to the doctor."

Four of five participants experienced negative feelings and problems related to menstruation. Most of the issues were derived from their daughters' disabilities, such as the lack of communication ability, lack of self-help skills, and so on.

Parents/caretakers communication related to menstruation management. One of the myths about females with DD is that they cannot manage menstruation themselves or

without assistance (Gomez, Carlson, & Dooren, 2012). In fact, many of them are able to manage menstruation independently with training or some of them are able to manage menstruation or self-care tasks with assistance (Rodgers & Lipscombe, 2005). All the five participants in this study tried to communicate with their daughters to teach menstruation management and four participants prepared their daughters' for their first menstruation in advance (talked about menstruation and how to manage it). Participant C was the only mother who did not provide any preparation for menarche and the level of her daughter was severe while the others had mild or moderate disability.

***Preparation for menarche*.** Today, most of young females are taught and prepared for menstruation before their menarche (first menstruation). According to Swenson and Havens (1987), it is important to provide information to females with DD for effective menstrual preparation even though it is not certain that they will understand. All of the participants in the interview study did a good job of preparing their daughters for menstruation except Participant C as stated above.

Participants A, B, and D talked about menstruation and tried to teach their daughters how to manage it. Participant A stated: "We practiced with the pad quite a bit before she started, to learn where to place it, where to put it." According to Participant B, "I think we had talked about it a little bit. So that she knew that you knew when she was getting close to the first period." Participant D said that "we had taught her beforehand. Like kind of what to expect we got out some pads and kind of you know showed her how to put them in her underwear and this is a normal thing that's going to happen and this is what it looks like and you know all that type of stuff. And she came downstairs and said "Mom! I got my period."

Some of the participants used different strategies. Participant C created communication symbols and put them together in a book for her daughter to teach her about menstruation, while Participant E developed a personalized story book about menstruation

based on the characteristics of their daughters' disabilities.

> *At least two years before she would menstruate we were already talking about it. Yeah because we anticipated that, first of all, she needed to know what to expect. Second of all we needed to know when she was ready. Then what we did then because we anticipated, we actually, you know, with age I knew when she would be hitting around eleven and twelve, you know things would start happening.* (Participant E)

Supports or resources. According to the literature, some mothers received assistance from others such as teachers and doctors, and had accessed information related to menstrual management during the pre-service training, through workshops or formal discussions and so on (Carlson & Wilson, 1994), while other mothers felt isolated and did not have any access to appropriate supports or resources for their menstruation management (Ditchfield & Burns, 2004; Saltonstall, 2007). This interview study showed the results consistent with the findings in the literature. In this study with five participants, some of them received and were able to access to the helpful supports and useful information related to menstrual management for their daughters and few of them complained that they wished they had had more supports and resources.

***Supports or resources received*.** All of the participants except Participant B mentioned that doctor was a good support. In particular, Participant A stated local Down syndrome clinic was also a good support along with her doctor. Participant E strongly recommended local health department as a support. According to Participant E, the local health department is run by qualified nurse practitioners and physicians. They do women's, infants', and children's health but their biggest focus is family planning and females' health. Also, every county has one so if her daughter was going to move someplace else, she didn't have to try to find another physician, she just had to find the local health department.

School teacher, school aide, and school nurse were also helpful as a part of supports

for Participants C and D. For Participant E, the school system really did not help her and her daughter regarding menstruation. She stated, “I believe that if she had done that little thing at school that they do a little bit.” Only Participant C, tried to seek help from a social network and online forum. She said that “Like a forum, you know, like an online forum or like a website that has shared what they have done or way they have overcome this and that problem and solution to the things that parents may have concerns with.”

Participant D attended a seminar in her local area which was on sexuality in children with disabilities and also she used the book, *teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality* (Couwenhoven, 2005) as a resource.

> *The biggest supports were the doctor and the school and then the books. And the doctor was very good at recommending good books for us. And then I got that extra book on approaching Down syndrome children about their bodies and sexuality and all that.* (Participant D)

***Supports or resources wanted by parents*.** Participant A wished to have more books on menstruation issues, not only for kids with special needs but also for parents. She searched Internet to find information related to menstruation issues, but there was not much out there. Her biggest wish was to have more materials available for parents to help their daughters prepare early to give them ideas and to make them comfortable with menstruation.

Participant C wanted some kind of training at home or with peers. She also stated that it would be best if she had a mentor, like someone around that age (girls with menstruation) so that she could make sure if she had done the right things and could get appropriate information for her daughter.

In conclusion, when the five participants were asked what would be the advice for other mothers or caretakers of females with DD, all of the participants suggested beginning preparation as early as possible. Even one mother who did not provide any preparation for her

daughter's menarche suggested early preparation for menstruation.

As part of the school services or programs on menstruation or general puberty education, individualized lesson plans would be necessary. One of the participants talked about a health class at her daughter's school. Her daughter with an autism spectrum disorder (ASD) had a general health class which included puberty and sex education, but it was not focused on an individual, one on one; therefore she never thought that it related to her because it was not directed personally to her. It would be critical to plan specific guidelines for individuals with disabilities when the school provides a general health class.

CHAPTER 5

Discussion

In most cultures**,** menstruation is often regarded negatively and as a taboo topic (Kelly & Gahagan, 2010). This may explain the paucity of research and lack of information on menstrual care for females with developmental disabilities (DD). The purpose of this study was to survey and interview parents or caretakers of females with DD about how to manage menstruation and what kinds of support (education or training) or help were needed or currently given to females with DD to manage menstruation.

To discuss the findings from the data, this chapter is arranged in four sections including: (a) summary of findings for the survey study; (b) summary of findings for the interview study; (C) limitations of the study; and (D) recommendations for future research.

Summary of Findings for the Survey Study

Research Question 1: What are the levels and traits among females with DD in terms of degree of independence, educational needs, and information accessibility related to menstrual care?

According to the data analysis of the interview study, there were significant differences between two groups of females with DD (mild or moderate: M/M group vs. severe or profound: S/P group) in degree of independence. The M/M group was more independent in menstrual care than the S/P group. This finding may explain the significant differences between the two groups in educational needs. Since the M/M group was more independent, this may mean that they were more capable to be taught or trained. Their parents or caretakers tried to seek more training or teaching for menstrual management skills for their females with DD. The differences in educational needs could also mean that the S/P group needed specialized, individualized or more intense supports or resources in menstrual management which were not available or perhaps a lack of awareness of the existence of such

resources to request.

As table 7 shows, there was no significant difference in resource preferences between the two groups except for “Brochure” both before first menstruation and after first menstruation. The M/M group preferred a “Brochure” as a resource while the S/P group did not prefer this either before or after first period. This may mean that the S/P group needed more physical help rather than print or other media resources. As the results showed, it would be necessary to identify uniquely appropriate services or resources for each group (M/M group and S/P group) in order to meet their expectations or needs on menstrual management.

Research Question 2: Are there any associations between degree of independence, educational needs, and information accessibility and disability-related characteristics (type and severity), after controlling for parents' or caretakers' socio-demographic characteristics (e.g., age, ethnicity, marital status, education level, employment)?

According to the results (Table 8), degree of independence and educational needs were associated with each other. Parents or caretakers of the females with mild or moderate DD (M/M group) were seeking more educational needs on menstrual management than did the other group (S/P group). Because females with more severe DD were less independent, they had different educational needs and expectations. As stated above, each group may need specifically, different types of supports or training for menstrual management.

Finally, most of the participants in this study tried to find information or resources for their females′ menstruation care. They were in agreement that it was not difficult to find what they wanted. Furthermore, they were satisfied with what they found. Since this was a survey study, it was not possible to probe further, such as the kinds of information and resources they looked for and what they found. This finding is not consistent with Saltonstall's (2007) conclusion. According to the Saltonstall's study (2007), caregivers had limited access to the intervention strategies and environmental supports for teaching menstrual care even though

there had been successful empirical interventions for menstrual self-care to the population with DD in previous decades (Demetral, Driessen & Goff, 1983; Hamilton et al., 1969; Richman et al., 1986; Richman et al., 1984).

No research has been studied on what kinds of information, resources, or supports for different severity levels of DD are needed for menstrual management. The Chou et al.'s (2009) and Rodgers et al.'s (2001) studies compared of different kinds of menstrual symptoms or problems with level of intellectual disability. Hence, further study on this topic would be suggested to provide better supports for each group (mild, moderate, severe, and profound) for menstrual management.

Research Questions Related to the Interview Study

Research Question 1: How do levels of disability affect parents' or caretakers' expectations of menstruation management?

The levels of understanding of menstruation appear to affect learning of menstrual self care (Mason & Cunningham, 2008). There were three mothers (Participants A, D, and E) of females with mild DD, one mother (Participant B) of a female with moderate DD, and one mother (Participant C) of a female with severe DD participated in the interview study. Participant C was the only mother who did not prepare for the first menstruation and expressed a lot of worry and concerns about her ability to communicate effectively with her daughter. She finally developed a special communication book, using picture symbols, to communicate with her daughter and teach her menstraul management skills. On the other hand, Participant B, whose daughter had moderate DD, had a easy transition and no problems with teaching her menstrual management self-care. The only thing she did was talk to her daughter about what menstruation is and how to manage it.

According to Mason and Cunningham (2008), how much the females with Down syndrome have been told about the information of menstruation affected a function of

menstrual management. This finding was the same as other studies (Ditchfield, 2004; Rodgers, 2001; Scola &Pueschel, 1992). Due to the lack of knowledge about menstruation, many females with DD are not given enough information about menstruation. Hence, it is recommended to provide some explanations of menstruation cycle for females with DD to help them better understand it based on their appropriate comprehension levels (Mason & Cunningham, 2008).

Research Question 2: What kinds of problems do the parents/caretakers and females with DD experience with menstruation?

As mentioned in the literature review (Chapter 2), females with DD have reported emotional, physical, and management problems related to menstruation, such as pain, heavy periods, lengthy or irregular periods, behavior and mood changes, negative reactions, hygiene problems, self-care, and other problems (Carlson & Wilson, 1994, 1996; Chou et al., 2008, Ditchfield & Burns, 2004; Epps, Stern, & Horner, 1990; Griffin, Carlson, Taylor, & Wilson, 1994; Mason & Cunningham, 2008; Rodgers & Lipscombe, 2005; Rodgers et al., 2006; Saltonstall, 2007). In this interview study, some females with DD experienced headaches, cramps, and behavior, mood, and appetite changes. Four of five participants experienced negative feelings and problems related to menstruation.

Mason and Cunningham (2008) suggested that better preparation, education, and training might reduce some mothers' distress or problem experiences with their daughters' menstruation. Specifically, they suggested the need for resources explaining how to train and set up routines for the menstruation cycle as a preparation for their daughters might reduce their difficulties. Finally, good communication and collaboration between schools and homes in order to ensure the most effective preparation were strongly suggested (Mason & Cunningham, 2008).

Research Question 3: What kinds of support do parents/caretakers want to receive for

females with DD?

The results indicated that the participants wanted to have more books about menstruation for both parents and females with DD, websites with useful information related to menstruation, more materials for parents of females with DD to prepare early, a mentor to get help, and a social group (support group) comprised of others who are in the same situation so that they can exchange their experiences and information. One mother mentioned that her daughter's doctor was a very helpful supporter to manage her menstrual care; however, she needed additional help (such as a specialist) between home and hospital in order to apply the strategies or interventions the doctor suggested to her.

Similarly, the Saltonstall's study (2007) indicated that mothers also preferred schools and medical offices for accessing social and educational supports about menstruation. The suggested services and supports were (a) anticipation and preparation for menarche, (b) strategies for supporting self-care during menstruation, (c) opportunities for parents of maturing students with disability to connect with one another, and (d) issues related to fertility and safety (Saltonstall, 2007).

Research Question 4: How did parents/caretakers communicate with girls with DD to manage menarche or menstruation?

As previously stated, in western cultures, menstruation is not discussed openly except in some limited circumstances. Yet, communication plays an important role for females with DD as a preparation of menarche and menstrual management (Rodgers et al., 2006). In this interview study and in the Saltonstall's study (2007), most mothers tried to communicate with their daughters with DD to prepare menarche and teach menstrual management. In contrast, some mothers of females with severe or profound DD did not try to communicate with their daughters due to their lack of comprehension skills and limited communication ability.

As stated in Research Question 1, Mason and Cunningham (2008) suggested that appropriate comprehension levels of communicating (explanation of menstruation) with females with DD would help them for a better understanding of menarche and menstrual management. Thus, it would be recommended to provide effective communication tools or strategies to the parents and caretakers of females with severe or profound DD and encourage them to communicate with their females with DD to teach menarche and menstruation management.

Research Question 5: What systems of support did the mothers have access to during the transition to menarche? Were those supports helpful?

As the Saltonstall's study (2007) indicated above, the mothers in this interview study also preferred and received successful supports from hospital or local health department about menstruation. On the other hand, some mothers received supports from the school teacher, nurse, and classroom aide. They complained that they wished they had had school services more involved in their females' menstruation education and training. Also, some mothers said books, social networks, and online forums were helpful resources to learn about females' menstruation.

The Chou and Lu' study (2012) illustrated that due to the limited support networks, some mothers developed their own strategies for managing their daughter's menstruation. In this study, one mother (Participant C) also could not find appropriate resources and supports. Hence she developed her own communication system (using picture symbols) to teach her daughter menstrual management skills. Although the supports for menstrual management for females with DD have been available through various sources (medical, educational, social network, books and so on), they are not sufficient enough to help parents and caretakers or females with DD deal systemically and specifically with the issues. Some studies (Epps et al., 1990; Gray & Jilich, 1990; Llewelyn-Scorey, 1989; Richman et al., 1984) suggested

consideration of individualized preparation and ongoing supports for females with DD. The future support systems should consider the needs for each different level of disabilities and different characteristics of disabilities.

Limitations of the Study

Because no established measures exist for the use with special populations on menstrual management, a questionnaire was developed specifically for use in this study. Since the questionnaire has not been validated, it might raise some questions about reliability and validity of the current findings. Thus, a well-defined and validated measure will be impor tant for future studies.

In order to obtain a broad range of participations through the states, an online survey was chosen for this study. The limitations of online survey research are (a) the environments of web-based surveys cannot be controlled or monitored (Daley et al., 2003), (b) the response rates of online surveys are significantly lower than other types of surveys (in-person or paper-and-pencil surveys) (Couper, 2007). Online survey affects the response rate of participants such that they discourage the participants who are not familiar with technology or who do not have a computer to access the internet (Kypri et al., 2004). There is also participant bias due to financial, educational, or technological expertise that enters into volunteering to participate in an online survey.

The use of a non-probability sampling and the participation of only volunteers may limit generalization of the current findings. Including those parents and caretakers who could not be reached or refused to participate for the survey may yield different outcomes. Thus, it is important for future studies to design and implement proper sampling methods that embrace participants with diverse socio-demographic and cultural backgrounds and from different locations.

Recommendations for Future Research

In order to provide successful and effective supports for parents or caretakers and females with DD on menstrual management, future research should consider all aspects and see all the different points of view on individuals' needs for menstrual management. Specifically, different types of interventions or supports are needed for each level of disabilities (mild, moderate, severe, and profound) and each type of developmental disabilities (intellectual disability, autism spectrum disabilities, Down syndrome, cerebral palsy, and blindness). In addition, it will be important to identify what kinds of appropriate services, information, or supports caretakers (parents, siblings, teachers, professionals, and so on) need to take care of their females with DD on menstrual management.

These days, the number of Internet users has rapidly increased due to the development of smart phones, tablets, and laptops. This trend seems to affect people in the field of special education. As some participants indicated in the interview study, online support is one of the most familiar and important resources in order to obtain their help. To satisfy their needs, it would be necessary to develop online modules that demonstrate all the information and procedures related to menstrual management for females with DD. Autism Internet Module (AIM) from the Ohio Center for Autism and Law Incidence (OCALI) is a good example. This module covers a variety of topics. Each module gives guidance through case studies, instructional videos, pre- and post-assessments, a glossary, and so on. These are available free. It would be helpful not only for females with DD but also for their parents or careers if an Internet module for menstrual management is developed and available for them.

In conclusion, although there are available resources and supports for menstruation management for parents or females with DD, the results in this study (from both the survey and interview studies) indicated that parents of females with DD still needed more resources and supports. In order to satisfy their needs for menstrual management, more practical and

evidence-based resources should be studied and published in order to be effectively disseminated for them.

References

AboutKidsHealth. (2004–2013). Menstruation and mental disability: Advice for parents of adolescent girls. Retrieved from http://www.aboutkidshealth.ca/En/HealthAZ/DevelopmentalStages/Tweens/Pages/Menstruation-and-Mental-Disability-Advice-for-Parents-of-Adolescent-Girls.aspx.

Adams, B., Wilgosh, L., & Sobsey, D. (1990). Sorrow or commitment: The experience of being the parent of a child with severe disabilities. *Developmental Disabilities Bulletin, 18*, 49–58.

Alcorn, D. E. (1974). Parental views on sexual development and education of the trainable mentally retarded. *Journal of Special Education, 8*, 119–130.

American Academy of Pediatrics (1999). Committee on genetics: Folic acid for the prevention of neural tube defects. *Pediatrics, 104*, 325 –327.

American Psychiatric Association. (2000). *Diagnostic and statistical manual for mental disorders* (4th ed., text revision). Washington, DC: American Psychiatric Publishing.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Ames, T. (1991). Guidelines for providing sexuality-related services to severely and profoundly retarded individuals: The challenge for the nineteen-nineties. *Sexuality and Disability, 9*, 113–122.

Azrin, N. H., & Foxx, R. M. (1971). A rapid method of toilet training the institutionalized retarded. *Journal of Applied Behavior Analysis, 4*, 89–99.

Backeljauw, P., Rose, S., & Lawson, M. (2004). Clinical management of menstruation in adolescent females with developmental delay. *The Endocrinologist, 14*, 87–92.

Backstrom, T. (1976). Epileptic seizures in women related to plasma estrogen and progesterone during the menstrual cycle. *Acta Neurol Scand, 5*, 321–347.

Barton, E. S., Guess, D., Garcia, E., & Baer, D. M. (1970). Improvement of retardates' mealtime behaviors by timeout procedures using multiple-baseline techniques. *Journal of Applied Behavior Analysis, 3*, 77–84.

Bass, M. D. (1978). Surgical contraception: A key to normalization and prevention. *Mental Retardation, 16*, 339–404.

Baxley, D. & Zendell, A. (2005). *Sexuality education for children and adolescents with developmental disabilities: An instructional manual for educators of individuals with developmental disabilities, sexuality across the lifespan*. Tallahassee, FL: Florida Developmental Disabilities Council, Inc. Retrieved from http://www.albany.edu/aging/IDD/documents/parentworkbook.pdf.

Beausang, C. C., & Razor, A. G. (2000). Young western women's experiences of menarche and menstruation. *Health Care for Women International, 21*, 517–528.

Bender, M., & Valletutti, P. J. (1976). *Teaching the moderately and severely handicapped* (Vol. I). Baltimore, MD: University Park Press.

Bender, M., Valletutti, P. J., & Bender, B. (1976). *Teaching the moderately and severely handicapped* (Vol. II). Baltimore, MD: University Park Press.

Brooks-Gunn, J., & Ruble, D. (1982). The development of menstrual-related beliefs and behaviors during early adolescence. *Child Development*, 1567–1577.

Buck v. Bell. 374 U.S. 200 (1927).

Burke, L. M., Kalpakjian, C. Z., Smith, Y. P., & Quint, E. H. (2010). Gynecologic issues of adolescents with Down syndrome, autism, and cerebral palsy. *Journal of Pediatric and Adolescent Gynecology, 23*, 11-15.

Cambridge, P., & Mellan, B. (2000). Reconstructing the sexuality of men with learning disabilities: Empirical evidence and theoretical interpretations of need. *Disability and Society, 15*, 293–311.

Carlson, G. (2002). Supporting the health and well being of people with intellectual disability and high support needs through networking and resource development. *Australian Occupational Therapy Journal, 49,* 37–43.

Carlson, G., & Wilson, J. (1994). Menstrual management: The mother's perspective. *Mental Handicap Research, 7*, 51–63.

Carlson, G., & Wilson, J. (1996). Menstrual management and women who have intellectual disabilities: Service providers and decision-making. *Journal of Intellectual and Developmental Disability, 21*, 39–57.

Chou, Y., & Lu, Z. (2012). Caring for a daughter with intellectual disability in managing menstruation: Mother's perspective. *Journal of Intellectual and Developmental Disability, 37*, 1–10.

Chou, Y., Lu, Z., Wang, F., Lan, C., & Lin, L. (2008). Meanings and experiences of menstruation: Perceptions of institutionalized women with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 21*, 575–584.

Clarke, A., & Ruble, D. (1978). Young adolescents' beliefs concerning menstruation. *Child Development*, 231–234.

Costos, D., Ackerman, R., & Paradis, L. (2002). Recollections of menarche: Communication between mothers and daughters regarding menstruation. *Sex Roles, 46*, 49–59.

Couper, M. P. (2007). *Whither the web: Web 2.0 and the changing world of web surveys*. Paper presented at the meeting of the Association for Survey Computing. University of Southampton, UK.

Couwenhoven, T. (2007). *Teaching children with Down syndrome about their bodies, boundaries, and sexuality: A guide for parents and professionals*. Bethesda, MD: Woodbine House.

Crain, L. S. (1980). Sterilization and the retarded female: Another perspectice. *Pediatrics, 66*,

650–651.

Creswell, J. W. (1994). *Research design: Qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.

Creswell, J. W. (1998). *Qualitative inquiry & research design: Choosing among five approaches.* Thousand Oaks, CA: Sage.

Cynkar, R. J. (1981). Buck v. Buck: "Felt necessities" v. fundamental values? *Columbia Law Review, 81*, 1418–1461.

Daley, T. C., Whaley, S. E., Sigman, M. D., Espinosa, M. P., & Neumann, C. (2003). IQ on the rise: The Flynn effect in rural Kenyan children. *Psychological Science, 14*, 215–219.

Demetral, G. D., Driessesn, J., & Goff, G. A. (1983). A proactive training approach designed to assist developmental disabled adolescents deal effectively with their menarche. *Sexuality and Developmental Disability, 6*, 38–46,

Department of Health, Education, and Welfare (DHEW) proposes 30-day waiting period for sterilization; No funds for under 2/5. Contraceptive hysterectomies. (1978). *Family Planning Perspectives, 10*, 39.

Ditchfield, H., & Burns, J. (2004). Understanding our bodies, understanding ourselves: The menstrual cycle, mental health and women with learning disabilities. *Tizard Learning Disability Review, 9*, 24–32.

Dizon, C., Allen, L., & Ornstein, M. (2005). Menstrual and contraceptive issues among young women with developmental delay: a retrospective review of cases at the Hospital for Sick Children, Toronto. *Journal of Pediatric and Adolescent Gynecology, 18*, 157–162.

Dowben, C., & Heartwell, S. F. (1979). Legal implications of sterilization of the mentally retarded. *American Journal of Disease of Children, 133*, 697–699.

Elias, E. R., & Sadeghi-Nejad, A. (1994). Precocious puberty in girls with mylodysplasia. *Pediatrics, 93,* 521–522.

Ellis, N. R. (1975). Issues in mental retardation. *Law and Psychology Review, 1*, 9–16.

Epps, S., Stern, R., & Horner, R. (1990). Comparison of simulation training on self and using a doll for teaching generalized menstrual care to women with severe mental retardation. *Research in Developmental Disabilities, 11*, 37–66.

Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*, 175–191.

Gall, M. D., Gall, J. P., & Borg, W. R. (2003). *Educational research: An introduction* (7th ed., pp. 435–472). Boston, MA: Allyn & Bacon.

Gill, C., Kirschner, K., & Reis, J. (1994). *Health services for women with disabilities: Barriers and portals. Reframing women's health.* Thousand Oaks, CA: Sage.

Girardeau, F. L., & Spradlin, J. E. (1964). Token rewards in a cottage program. *Mental Retardation, 13*, 345-351.

Gray, J., & Jilich, J. (1990). *Guidelines in Menstrual Management: A handbook for parents and carers of girls and young women with special learning needs.* Carlton, Victoria: Social Biology Resources Centre - since 1993, known as Center for Social Health, Fairfield. (Part of a resource package titled Janet’s Got Her Period)

Griffin, J., Carlson, G., Taylor, M., & Wilson, J. (1994). Menstrual management and intellectual disability: new perspectives. *Occupational Therapy International, 1*, 141-157.

Hamilton, J., Allen, P., Stephens, L., & Davall, E. (1969). Training mentally retarded females to use sanitary napkins. *Mental Retardation, 7*, 40-43.

Hammar, S. L., & Barnard, K. E. (1966). The mentally retarded adolescent. A review of the

characteristics and problems of 44 non-institutionalized adolescent retardates. *Pediatrics, 38,* 845-857.

Hamre-Nietupski, S., & Williams, W. (1977). Implementation of selected sex education and social skills to severely handicapped students. *Education and Training of the Mentally Retarded, 12,* 364-372.

Havens, B., & Swenson, I. (1986). Menstrual perceptions and preparation among female adolescents. *Journal of Obstetrics, Gynecology & Neonatal Nursing, 15,* 406-411.

Hawley, D., & DeHaan, L. (1996). Toward a definition of family resilience: Integrating life-span and family perspectives. *Family Process, 35*, 283-298.

Heger, S., Sippell, W. G., & Partsch, C. J. (2005). Gonadotropin-releasing hormone analogue treatment for precocious puberty: twenty years of experience. *Endocrine Development, 8*, 94–125

Homer, R. D., & Keilitz, I. (1975). Training mentally retarded adolescents to brush their teeth. *Journal of Applied Behavior Analysis, 8*, 301–309.

Kempton, W., & Kahn, E. (1991). Sexuality and people with intellectual disabilities: A historical perspective. *Sexuality and Disability, 9*, 93–111.

Klett, L. S., & Turan, Y. (2012) Generalized effects of social stories with task analysis for teaching mesntrual care to three young girls with autism. *Sexuality and Disability, 30*, 319–336.

Koff, E., & Rierdan, J. (1995). Early adolescent girls' understanding of menstruation. *Women & Health, 22,* 1–19.

Krassas, G., Pontikides, N., Kaltsas, T., Papadopoulou, P., Paunkovic, J., Paunkovic, N., et al. (1999). Disturbances of menstruation in hypothyroidism. *Clinical Endocrinology, 50,* 655–659.

Kvale, S. (1996). *Interviews*. Thousand Oaks, CA: Sage.

Kypri, K., Saunders, J. B., Williams, S. M. et al. (2004). Web-based screening and brief intervention for hazardous drinking: A double-blind randomized controlled trial. *Addiction, 99,* 1410–1417.

Lahmeyer, H. M., Miller, M., & DeLeon-Jones, F. (1982). Anxiety and mood fluctuation during the normal menstrual cycle. *Psychosomatic Medicine, 44,* 183–193.

Llewelyn-Scorey, C. (1989). Traning in menstrual management. *In Community Bulletin, Intellectual Disability Services, Queensland, 13,* 11–13.

McNamara, V. P., Scoggin, W. A., & Raskin, F. (1974). Sterilization of the mentally retarded at the Medical College of Georgia, under law no. 1288. *Journal of the Medical Association of Georgia, 63,* 327–331.

Mason, L., & Cunningham, C. (2008). An exploration of issues around menstruation for women with Down syndrome and their carers. *Journal of Applied Research in Intellectual Disabilities, 21,* 257–267.

Marshall, C., & Rossman, G. B. (1989). *Designing qualitative research.* Thousand Oaks, CA: Sage.

Merriam, S. B. (1998). *Qualitative research and case study applications in education*. San Francisco, CA: Jossey-Bass.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis* (2nd ed). Thousand Oaks, CA: Sage.

Minge, M. R., & Ball, T. S. (1967). Teaching of self-help skills to profoundly retarded patients. *American Jouranl of Mental Deficiency, 71,* 864–868.

Moos, R. (1968). The development of a menstrual distress questionnaire. *Psychosomatic Medicine, 30,* 853–886.

Morse, J., & Doan, H. (1987). Adolescents' response to menarche. *Journal of School Health, 57,* 385–389.

Morse, J. M., & Field, P. A. (1995). *Qualitative research methods for health professionals* (2nd ed.). Thousand Oaks, CA: Sage.

New South Wales Council for Intellectual Disability. (2010). retrieved from http://www.nswcid.org.au/health/se-health-pages/managing-menstruation.html.

O'Hara, J. B., & Sanks, T. H. (1956). Eugenic sterilization, *Georgetown Law Journal, 45*, 36–37.

Oshima, S., Kirschner, K., Heinemann, A., & Semik, P. (1998). Assessing the knowledge of future internists and gynecologists in caring for women with tetraplegia. *Archives Physical Medicine and Rehabilitation, 79*, 1270–1276.

Paige, K., Paige, J., & Fuller, L. (1981). *The politics of reproductive ritual*. Berkeley, CA: University of California Press.

Park, H. (2011). *Menstrual management quetsionnaire for parents/caretakers (MMQ-P/C)* Unpublished manuscript.

Parlee, M. B. (1974). Stereotypic beliefs about menstruation: A methodological note on the Moos Menstrual Distress Questionnaire and some new data. *Psychosomatic Medicine, 36*, 229–240.

Perrin, J. C., Sands, C. R., Tinker, D. E., Dominquez, B. C., Dingle, J. T., & Thomas, M. J. (1976). A considered approach to sterilization of mentally retarded youth. *American Journal of Diseases of Children, 130*, 288–290.

Prété1, G., Couto-Silva1, A., Trivin, C., & Brauner, R. (2008). Idiopathic central precocious puberty in girls: Presentation factors. *BMC Pediatrics, 8*, 1–8.

Quint, E., Elkins, T., Sorg, C., & Kope, S. (1999). The treatment of cyclical behavioral changes in women with mental disabilities. *Journal of Pediatric and Adolescent Gynecology, 12*, 139–142.

Quint, E. H., Breech, L., Bacon, J., & Schwandt, A. (2006). Management quandary:

Menstrual issues in a teenager with developmental delay. *Journal of Pediatric and Adolescent Gynecology, 19,* 53–55.

Richman, G. S., Ponticas, Y., Page, T. J., & Epps, S. (1986). Simulation procedures for teaching independent menstrual care to mentally retarded persons. *Applied Research in Mental Retardation, 7,* 21–35.

Richman, G. S., Reiss, M. L., Bauman, K. E., & Bailey, J. S. (1984). Teaching menstrual care to mentally retarded women: acquisition, generalization, and maintenance. *Journal of Applied Behavior Analysis, 17,* 441–451.

Robson, C. (1993). *Real world research.* Malden, MA: Blackwell.

Rodgers, J., & Lipscombe, J. (2005). The nature and extent of help given to women with intellectual disabilities to manage menstruation. *Journal of Intellectual & Developmental Disability, 30,* 45–52.

Rodgers, J., Lipscombe, J., & Santer, M. (2006). Menstrual problems experienced by women with learning disabilities. *Journal of Applied Research in Intellectual Disabilities, 19,* 364–373.

Roxburgh, D. R., & West, M. J. (1973). The use of the norethisterone to supress menstruation in the intellectually severely retarded woman. *The Medical Journal of Australia, 2,* 310–313.

Saltonstall, B. (2007). Mothers raising daughters with cognitive delay: Reflections on menarche & menstruation. *Women's Health and Urban Life, 6,* 41–59.

Saltonstall, B. (2009). *Coming of age: Supporting girls with developmental disability through the transition to menstruation* (Doctoral dissertation). Available from ProQuest Dissertations and Theses database. (UMI No. 0821898).

SAS Institute. (2002–2010). *SAS/STAT 9.3 user's guide*. Cary, NC: SAS Institute Inc.

Savasi, I., Spitzer, R. F., Allen, L. M., & Ornstein, M. P. (2009). Menstrual suppression for

adolescents with developmental disabilities. *Journal of Pediatric & Adolescent Gynecology, 22*, 143–149.

Scola, P. S. & Pueschel, S. M. (1992). Menstrual cycles and basal body temperature curves in women with Down syndrome. *Obstetrics and Gynecology 79*, 91–94.

Shainess, N. (1961). A re-evaluation of some aspects of femininity through a study of menstruation: A preliminary report. *Comprehensive Psychiatry, 2*, 20–26.

Shropshire, L., Morris, W. M., & Foote, E. L. (1967). Suppression of menstruation: A hygiene measure in the care of mentally retarded patients. *Journal of the American Medical Association, 200*, 144–145.

Siddiqi, S. U., Van Dyke, D. C., Donohoue, P., & McBrien, D. M. (1999). Premature sexual development in individuals with neurodevelopment disabilities**.** *Developmental medicine and child neurology, 41*, 392–395.

Silber, T., Batshaw, M. L. (2004). Ethical dilemmas in the treatment of children with disabilities. *Pediatric Annals, 33*, 752–761.

Sorensen-burnworth, R. J., & Bing, N. (2008). *Menstruation training and adolescent with autism*. Paper presented at Annual Convention of The Association for Behavior Analysis at the 33rd Conference. Abstract retrieved from http://www.abainternational.org/conv2007/program/ViewEvent.asp?intEventID=488&blnShowAddToSchedule=False&blnShowRateEvent=False.

Sulpizi, L. (1996). Issues in sexuality and gynecologic care of women with developmental disabilities. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 25*, 609–614.

Swenson, I., & Havens, B. (1987). Menarche and menstruation: A review of the literature. *Journal of Community Health Nursing, 4*, 199–210.

Turchin, G. (1974). Sexual attitudes of mothers of retarded children. *Journal of School Health, 44*, 490–492.

Vitello, S. J. (1978). Involuntary sterilization: Recent developments. *Mental Retardation, 16,* 405–409.

Werner, P. (1988). Terminating the rights of mentally retarded parents: Severing the ties that bind. *Journal of Marshall Law Review, 22*, 133–137.

West, R. R. (1977). Sterilization of mentally retarded women. *The Medical Journal of Australia, 1,* 830.

Whisnant, L., & Zegans, L. (1975). A study of attitudes toward menarche in white middle-class American adolescent girls. *American Journal of Psychiatry, 132*, 809–814.

Williams, L., & Nind, M. (1999). Insiders or outsiders: Normalisation and wominen with learning difficulties. *Disability & Society, 14*, 659–668.

Wilcoxon, L. A., Schrader, S. L., & Sherif, C. W. (1976). Daily self-reports on activities, life events, moods, and somatic changes during the menstrual cycle. *Psychosomatic Medicine, 38,* 299–417.

Worley, G., Houlihan, C. M., & Herman-Giddens, M. E. et al. (2002).Secondary sexual characteristics in children with cerebral palsy and moderate to severe motor impairment: A cross-sectional survey. *Pediatrics, 110,* 897–902.

Yeargin-Allsopp M., Murphy, C. C., Oakley, G. P., & Sikes, R. K. (1992). A multiple-source method for studying the prevalence of developmental disabilities in children: The metropolitan Atlanta developmental disabilities study. *Pediatrics, 89,* 624–630.

Zelman, D., & Tyser, K. M. (1979). *Essential adult sex education for the mentally retarded,* (2nd ed.). Madison, WI: James Stanfield Film Associates.

Appendix A

Human Subjects Committee Approval

KU RESEARCH & GRADUATE STUDIES
The University of Kansas

1/12/2012
HSCL #19777

Hye Ran Park
455 Hutton Cir.
Lawrence, KS 66049

The Human Subjects Committee Lawrence Campus (HSCL) has received your response to its expedited review of your research project

19777 Park/Griswold (SPED) Menstrual Support for Females with Mild and Moderate Developmental Disabilities: Survey and Interveiw for Parents or Caretakers

and approved this project under the expedited procedure provided in 45 CFR 46.110 (f) (7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. As described, the project complies with all the requirements and policies established by the University for protection of human subjects in research. Unless renewed, approval lapses one year after approval date.

The Office for Human Research Protections requires that your consent form must include the note of HSCL approval and expiration date, which has been entered on the consent form(s) sent back to you with this approval.

1. At designated intervals until the project is completed, a Project Status Report must be returned to the HSCL office.
2. Any significant change in the experimental procedure as described should be reviewed by this Committee prior to altering the project.
3. Notify HSCL about any new investigators not named in original application. Note that new investigators must take the online tutorial at http://www.rcr.ku.edu/hscl/hsp_tutorial/000.shtml.
4. Any injury to a subject because of the research procedure must be reported to the Committee immediately.
5. When signed consent documents are required, the primary investigator must retain the signed consent documents for at least three years past completion of the research activity. If you use a signed consent form, provide a copy of the consent form to subjects at the time of consent.
6. If this is a funded project, keep a copy of this approval letter with your proposal/grant file.

Please inform HSCL when this project is terminated. You must also provide HSCL with an annual status report to maintain HSCL approval. Unless renewed, approval lapses one year after approval date. If your project receives funding which requests an annual update approval, you must request this from HSCL one month prior to the annual update. Thanks for your cooperation. If you have any questions, please contact me.

Sincerely,

Stephanie Dyson Elms
Coordinator
Human Subjects Committee Lawrence

cc: Deborah Griswold

Appendix B

Letter for Organizations of Developmental Disabilities

Name of the person
Director of the Organization
Address or email address

Date

Dear _____

Hello! My name is Hye Ran Park. I am a doctoral candidate in special education at the University of Kansas. I am currently working on my dissertation research about *menstrual impact for females with mild and moderate developmental disabilities*. As you know there is little information or guidance for the parent or caretaker regarding the preparation of the young female for menstruation or about how to help her care for herself to whatever degree the young woman can.

I plan to conduct an online survey for parents or caretakers of females with developmental disabilities about this topic. By gathering this information, my hope is that this study will ultimately provide information and support for families/caretakers of females with mild to moderate developmental disabilities on this very personal and sensitive issue. Menstruation is a topic that under the best circumstances is difficult to talk about. For our young females with disabilities it is that much more difficult and challenging a subject to problem-solve. For all females my hope is to help them be as independent as possible and be treated with respect and dignity.

In order to recruit the participants, I'm asking if you are willing to post an announcement with a brief study description on your website or on-line/off-line newsletter so that your organization members can read the announcement of the study. My hope is that by recruiting a large group of participants I will be able to shed light on this subject and perhaps develop information or suggestions that families will find useful.

Thank you for considering my study and I look forward to hearing from you. I have attached the announcement of my study and the link to the survey.

Sincerely,

Hye Ran Park

University of Kansas Special Education Department
Joseph R. Pearson Hall,5th floor
1122 West Campus Rd.
University of Kansas
Lawrence, KS 66045-3101
E-mail : blueran@ku.edu
Cell Phone : 785-218-1664

Appendix C

Survey about Menstruation (period) of Girls with Developmental Disabilities

Survey about Menstruation (period) of Girls with Developmental Disabilities

Thank you so much for your interest in this study! Parents/Caretakers are invited to participate in a survey about the topic of Menstruation (period) of Girls with Developmental Disabilities. This survey is being conducted by Hye Ran Park, a doctoral candidate in special education at the University of Kansas.

What is the purpose of this study?

As you know, menstruation (period) is one of the puberty symptoms for every female regardless of whether or not a disability is present. However, there is little information or guidance for the parent or caretaker regarding the preparation of the young female with developmental disability for menstruation (periods) or about how to help her care for herself to whatever degree the young females can. Thus, your help and participation are needed in this survey in order to provide valuable information and support for families of females with developmental disabilities about menstruation (periods).

What does this study involve?

This study involves the completion of an online survey. If you agree to participate in this survey:

- You will follow the link to the **SurveyMonkey™** website to find the survey
- This survey should take no longer than 30 minutes to complete

Please proceed to https://www.surveymonkey.com/s/PMPRWKR

If you have any questions, please contact below

Thank you so much!

Hye Ran Park
E-mail : blueran@ku.edu
Cell Phone : 785-218-1664

Appendix D

Demographic Information

Demographic Information

- **Please read the questions and then check the applicable box(es) or answer the questions.**
- **A "Female" in this form refers to a girl with moderate or severe disabilities who you care for.**

1. What is your relationship to the female with moderate or severe disabilities?

   □ Parent □ Legal Guardian □ Sibling □ Caretaker

   □ Other: _____

2. What is your gender?

   □ Male □ Female

3. What is your age range?

   □ 18 – 20 □ 21 -29 □ 30 – 39 □ 40 – 49 □ 50 – 59 □ above 60

   □ Other: _____

4. What country or state in US do you live?

   _____

5. What is your racial or ethnic background?

   □ African American □ Asian, Asian American □ Caucasian

   □ Latino, Hispanic, Mexican American □ Native American

   □ Pacific Islander □ Other: _____

6. What is your marital status?

   □Married □Single □Separated □Divorced □Widowed

7. What is the highest education level you have completed?

   □ Elementary school and under (K – 6 grade) □ Junior high school (7 – 9 grade)

   □ High School or Vocational high school (10 – 12 grade)

   □ Associate degree □ Bachelor's degree

□ Master's degree □ Doctorate degree

□ Other: _____

8. What is your current employment status?

□ Housewife/Husband □ Employed □ Unemployed □ Working at home

□ Other: _____

9. What is the female's diagnosis?

□ Autism spectrum disorder □ Intellectual disability (Mental retardation) □ Down syndrome □ Cerebral palsy □ Deafness □ Blindness

□ Other: _____

10. Her date of birth: _____mm/ _____dd/ _____yyyy

11. How would you describe the female's level of disabilities?

□ **Mild**: "IQ score ranges from 50-70, and they can often acquire academic skills up to the sixth-grade level. They can become fairly self-sufficient and in some cases live independently, with community and social support."

□ **Moderate**: "IQ score ranges from 35-55, and they carry out work and self-care tasks with moderate supervision. They typically acquire communication skills in childhood and are able to live and function successfully within the community in such supervised environments as group homes."

□ **Severe/Profound:** "IQ scores 20-40 or under 20-25, and they may master very basic self-care skills and some communication skills with appropriate support and training."

12. Is she able to communicate verbally?

□ Yes □ No □ Other: _____

13. Is she able to communicate with gestures?

□ Yes □ No □ Other: _____

14. Is she able to communicate with the communication devices?

□ Yes □ No □ Other: _____

15. Has the female started her first period?

□ No □Yes □ Other: _____

16. In the past six months, has her monthly menstrual cycle been regular?

□ Yes □No □ Don't know

17. Did/Does she have any kind medical treatments (medication, sterilization surgery and so on) to control or eliminate her menstrual (period) cycle?

□ Yes □ No □ Don't know

Appendix E

Menstrual Management Questionnaire for Parents/Caretakers

(MMQ-P/C)

Menstrual Management Questions for Caretakers of Females with Developmental Disabilities

- **From your observation and knowledge of the female about whom you are reporting, please respond to the following statements.**
- **"If your daughter (female) has not started her first period, please imagine your future and answer the questions."**
- **The following statements are about the degree of independence of your female's menstrual care.**

1. She identifies and communicate (verbally or gestures) that her period has started.

Never	Rarely	Sometimes	Often	Always	Do not Know
0	1	2	3	4	5

2. She manages cleanliness during her period independently (does not require assistance).

Never	Rarely	Sometimes	Often	Always	Do not Know
0	1	2	3	4	5

3. She buys pads/tampons most of the time without assistance.

Never	Rarely	Sometimes	Often	Always	Do not Know
0	1	2	3	4	5

4. She knows where to find pads/tampons in the home.

Never	Rarely	Sometimes	Often	Always	Do not Know
0	1	2	3	4	5

5. She changes pads/tampons during her period independently (does not require assistance).

Never	Rarely	Sometimes	Often	Always	Do not Know
0	1	2	3	4	5

6. She disposes of pads/tampons during her period most of the time.

Never	Rarely	Sometimes	Often	Always	Do not Know
0	1	2	3	4	5

- **The following statements are about teaching and support for your female's period (menstrual) management.**

7. I tried to teach or communicate with the female about period (menstrual) management skills **before** her first period.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
0	1	2	3	4	5

8. I tried to teach or communicate with the female about period (menstrual) management skills **after** her first period.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
0	1	2	3	4	5

9. My teaching or communication was successful to make the female understand period (menstrual) management skills.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
0	1	2	3	4	5

10. I want the female to have period (menstrual) management training or education from professionals

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
0	1	2	3	4	5

11. I want the female to have medical procedures to eliminate or alter her period rather than training or education.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
0	1	2	3	4	5

12. I need support and assistance from professionals about how to teach my female to manage her period.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
0	1	2	3	4	5

13. I am happy with the menstrual support (management training or menstrual education) that I received for my female from professionals

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
0	1	2	3	4	5

- **The following statements are about accessibility of information or resources related to period (menstrual) management.**

14. I have never tried to find resources for my female's period (menstrual) management.

Yes ____ No_____

15. A. Please write a number next to the 10 resources below to show your preference for **preparation** of the female's first period (menarche).

- Use 1 through 10: "**1**" is for your **most preferred** resource and "**10**" for the **least preferred**. (1 = most preferred, 10 = least preferred)

School teachers ( )

School nurse ( )

Doctors ( )

Nurses ( )

Internet ( )

Brochures ( )

Books ( )

DVDs ( )

Conferences/workshops ( )

Support group ( )

15. B. If you had another resource, what was that resources? Please list them.

_____

_____

16. Please write a number next to the 10 resources below to show your preference for the female's period (menstrual) management **after her first period**.

- Use 1 through 10: "**1**" is for your **most preferred** resource and "**10**" for the **least preferred**. (1 = most preferred, 10 = least preferred)

School teachers ( )

School nurse ( )

Doctors ( )

Nurses ( )

Internet ( )

Brochures ( )

Books ( )

DVDs ( )

Conferences/workshops ( )

Support group ( )

Others ( ) _____

16. B. If you had another resource, what was that resources? Please list them.

_____

_____

17. It was easy to find information or resources about **preparation** for the female's period (menstrual) management.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
0	1	2	3	4	5

18. It was easy to find information or resources for the female's period (menstrual) management **after her first period**.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
0	1	2	3	4	5

19. The information or resource I accessed were helpful for the female's period (menstrual) management.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
0	1	2	3	4	5

Thank you so much for your participation.

In order to obtain in-depth information, I would like to ask your willingness to volunteer for an interview. This interview is a part of the same project that you just participated in. I, Hye Ran Park, will interview you on the phone or Skype™ . There will be around 10 interview questions and it will take approximately 40 minutes. Your interview will be recorded using audio recordings and stored in a secure locked file cabinet in order to keep your privacy and confidentiality.

You have no obligation to participate and you may discontinue your involvement at any time.

If you agree to volunteer, please leave your contact information below.

- Email address:
- ID of Skype™ :
- Home Phone Number: ( ) _____ - _____
- Cell Phone Number: ( ) _____ - _____

Appendix F

Interview Consent Form

Interview Consent

Thank you for completing the on-line survey and indicating your willingness to participate in a follow-up interview. This interview will be conducted by telephone or Skype.

I am a doctoral candidate at the University of Kansas in the Department of Special Education; I am conducting a research project about menstrual support for females with developmental disabilities. I would like to interview you to obtain your views on menstrual support for females with developmental disabilities as a parent or caretaker.

There will be 10 interview questions and it will take approximately 40 minutes. Your interview will be recorded using *audio recordings and note-taking*. You have the option of *not* being audio recorded or the audio recording may be *stopped* at any time at your request!

As the researcher, only I and my research advisor will have access to the *audio recording and written notes*. Both the audio recording and the written notes will be stored in a *secure locked file cabinet* in order to keep your privacy and confidentiality. The audio recordings and written notes will be assigned a number therefore your name or other identifying information will not be associated with them. The recordings and notes will be *destroyed* as soon as the study is finished.

You have no obligation to participate and you may discontinue your involvement at any time.

Participation in the interview indicates your willingness to take part in this study and that you are at least 18 years old.

Should you have any questions about this project or your participation in it you may ask me or my faculty supervisor, Dr. Deborah Griswold, dgriz@ku.edu at the Department of School of Special Education.

If you have any questions about your rights as a research participant, you may call the Human Subjects Protection Office at (785) 864-7429 or email irb@ku.edu.